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ABSTRACT

The conference reports on early education of handicapped children includes nine major papers on aspects of early childhood education. First explained is the objective of the Bureau of Education for the Handicapped during the 1970's, followed by a paper that emphasizes the need for help for the child who has suffered early developmental disruption. The discussion on curriculum and evaluation development as a process for learning focuses on helping the child achieve his potential and on preventing secondary deficits. Elements of teacher accountability in program development and curriculum development for early childhood education of multiply handicapped children are covered in three papers. The next two papers discuss the mission of providing an early education, the government role, and child advocacy to various extents. Then explained is a service approach toward the improvement of programs for individuals with neuro-motor and sensory handicaps in addition to mental retardation. The Nassau preschool program for multiply handicapped children is described to be highly motivating for the children. Financing of educational programs, with emphasis on the federal level, is the last discussion. The remainder of the report concerns educational models from zero to 5 years of age. (CB)

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United Cerebral Palsy
Associations of New York State

in cooperation with

The State Education Department
Bureau for Physically Handicapped
Division for Handicapped Children

Presents

Proceedings on

Early Education of Handicapped Children

February 22, 23 and 24, 1972

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FOREWARD

This In-Service Training Program was made possible by the United States Office of Education and the New York State Education Department, Division of Handicapped Children, Bureau for Physically Handicapped.

The enclosed material is an attempt to document, with as much accuracy as possible, the results of a three day conference dealing with early educational opportunities for disabled children.

United Cerebral Palsy Affiliates throughout the State of New York have been operating classes for pre-school aged children, with a good deal of success, for the past five years, and offered to share their knowledge with those professionals who were not presently involved in this type of activity.

In addition, it was decided early in the planning stages, that the participants would be asked to re-think the entire early education question and attempt to develop new methods of delivering this vital service,as well as new methods of evaluating the effects of this service.

To this cause the program was dedicated, and it is the opinion of all the participants that our cause was achieved.

Special thanks must be extended to Mr. Raphael Simches; Dr. Zelda Kaye; Dr. Richard Hehir; and Mr. Robert Erb, without whose encouragement the program would not have been possible.

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OBJECTIVE OF THE BUREAU OF EDUCATION FOR THE HANDICAPPED FOR THE 70's

BY: FRANK B. WITHROW
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DIVISION OF EDUCATIONAL SERVICES
BUREAU OF EDUCATION FOR THE HANDICAPPED

There are two common factors that each of us share. We have all been members of a family unit, and we are all individual human beings of an inestimable worth. In the long history of mankind, the family and the individual have not always shared these distinctions. It has only been in the last two hundred years that any real meaning of the worth of the individual has been possible. Prior to this age, most people were either members of classes such as slaves, serfs, artisians or were identified primarily by their function within the social order. The importance of the individual and the importance of the family only began to be meaningful when collectively the social order was able to take care of the necessities of life such as food, shelter, and clothing. As man began to meet these basic needs, he began to have more time for consideration of his own worth, for consideration of his family unit, and for consideration of those people who were in the social order but were not able to contribute as fully as the average individual. It is only in recent times that the handicapped individual has been provided the opportunity of becoming a part of the social order and has been allowed to contribute his value to that social order.

I am sure that many of you are aware of the fact that in primitive societies the handicapped individual was considered unworthy and abandoned and discarded on the dumps of social debris. Even when people begain to have some feeling of consideration for handicapped individuals, the initial response to the handicapped was one of total care and total isolation of the individual within the social order. Aristotle, for instance, pointed out that the deaf or blind individual was to be considered a responsibility of the community, in other words, he was to become completely dependent upon the social order and to be cared for rather than abandoned. This was a major step in the direction of accepting the deaf or handicapped person as a part of the social order. However, the individual was not accepted as a worthy, free person, capable of participating on an equal basis within the social group. The history of the deaf was evolved from schools and residential care institutions where the child was considered useful, but a part of segregated environment. Some of our early residential institutions were designed primarily as sheltered environments set aside from the mainstream of activities. In such institutions, the individual was trained to contribute to his share of work and considered a part of the total sub-cultural group. It was not until the post World War II period that major efforts were made which encouraged deaf persons to develop in such a way as to enable them to take major places in society. Today, we find enumerable handicapped individuals that have risen to the rank of high social and economic responsibility both in working with other handicapped people and in the general market place.

We find deaf individuals active and concerned about the total minority cultural group of the deaf and their efforts at self-determination. This is a healthy attitude -- one that helps the development of the concept of worthiness on the part of the individual. As the handicapped person struggles to gain acceptance of his rightful place in the social order, he will have both failure and success. What does this have to do with you as a worker with handicapped children? How do these changes affect the various relationships that take place within the family when there is a handicapped member? The family can be and is considered a small duplication of the total social order. A family has a structure, it has rules, it has a cohesiveness that is similar to the total community. The ability of an individual to learn to live within a family, to accept his role within the family, and to participate as a worthy individual within the family, is a prelude to his ability to accept his rights as a citizen.

When we were primarily concerned with the care of handicapped children, our paternalistic institutionalized viewpoint of education made us, as professionals and as parents, guilty of allowing the institution to become the substitute parent. Many times the professionals and the institutions were all too ready to accept the total parental role and to allow the parents and the family abdicate their roles. Too often we have heard from older handicapped people that only when they came into a school setting did they find people that understood them, people that accepted them, and people that were able to communicate with them. Likewise, we find that the personnel of the institutions readily accepted this role as the substitute parent,and sometimes build a wedge between the child and his family. Part of the institution's response has been a self-fulfilling prophesy to prove to justify their existence. This is an unhealthy attitude and one that will still linger with us. We have to guard very carefully against such trends. The institution is primarily designed to serve not only the child but the family, and the child's needs as a member of that family. Institutions are not only schools and services, but also organizations that reportedly serve the interest of handicapped individuals and State and Federal agencies. It would be unforgiveable, for instance, if we merely substituted the parentalism of schools or institutions to Federal agencies or institutions and/or by national organizations. No one should be guilty of usurping this delicate relationship of the child and his parents to further the goals of the institutions.

We hear a great deal today about generation gaps. Today, it is popular to talk about the breakdown of the family and blame for a confused social order on the lack of family stability. I would like to difer with that viewpoint. Since the family no longer is a basic economic unit in an agricultural society, it no longer has the intensive 24-hour closeness that the agricultural unit had. On the other hand, it does have a much more broadly defined responsibility and a much more effective opportunity for interaction among the family members. There is more time to become intensely involved with our family members. Each family member can seek out and learn his own worth. Todays family has no real drudgery in the area of family maintenance. With more free time there is a greater opportunity for families to know each other.

The family is a small miniature of the social order of the community. Within the family the child learns who he is. The child has an opportunity to make mistakes and to be guided carefully in the correction of those mistakes. The child has an opportunity to feel and to explore interpersonal relations without, hopefully, great traumatic experiences. The family is theoretically a craddle of concern of love and affection. This, of course, does not mean that there will not be times when family members are extremely antagonistic towards one another. That too is a part of the learning process. The family and the family members will make mistakes because that is a part of the sheltered experimental community that the young child can live within and learn from. What is the goal of any child's life? Or, stated another way, what is the meaning of life within a society which emphasizes individual worth and individual freedom? One may spend his whole life seeking the answer to this question. To know oneself, to feel comfortable with oneself and to like oneself is the goal for most of us. What happens when the handicapped individual enters a family? How does the child develop, how does he act out, how does the family react to him and how does this affect his role in the family?

You will notice that I have mentioned the family as an example of the community. Community implies communication. It implies a togetherness and acceptance of the worthiness of the individual no matter what his physical characteristics or his limitations might be. Even in so called normal families, we know that the emotional environment of the family can be important to the child's growth. If it is bad, the child begins to distrust himself, to make poor adjustments and to identify with negative activities within that family's structure. When a child is identified as handicapped, there is the possibility of traumatic over reactions on the part of the family. These are frequently transmitted in non-verbal ways which can develop anxiety on the part of the child, and destroy his feelings of self-esteem. The child may interpret the anxiety of the family as being caused by his very handicap. It is extremely important that you learn early in life to live with the concept that your child is handicapped, that it is unfortunate but that it does not preclude a positive worth. It does not shut out opportunities for worthy experiences in life. On the contrary, it may open up avenues that were blocked for the family before. It may provide a real essence of what is meaningful in life. It may sharpen the interest of the family and enhance their cohesiveness as they work towards helping the handicapped child find his rightful place in life, I cannot over-emphasize the feelings of the emotional environment, since the emotional frame of the family is, probably the most important factor in success of all children. The child begins very early to understand the emotional climate of those people he is closest to. This is true not only for handicapped but for all children. An example of this has been some very interesting studies on children from minority groups. Black children who live in prejudice environments can, by the age of 3½ to 4 years, intuitively describe or perform in such manners that allow them to avoid storekeepers who are particularly prejudice.

This is done on an almost non-verbal, non-conscious basis. The same thing is true with the young child who has no formal means of communication, since he learns whether people are comfortable with him and accept him.

You, as parents, will be a part of many controversies that plague this field. You will hear people that advocate legislation that advocates different methodologies. You will hear and be advised as to the kinds of treatment that you should give your child. I say to parents that they and their child are the ultimate judges of the desirability of the advice that is given by professionals. They have a responsibility and a right to question anything that I or any other professional tells them. They have a right to demand that their child receives the education they feel, is desirable for him. They intuitively know whether their child is getting a fair shake in his educational placement. They will have developed those verbal and non-verbal means of communicating with your child. They will have set an atmosphere and a family constellation in which their child will grow up. What is it that is wanted for a handicapped child or for any child that is a member of your family? I can tell you what I want for my children. Only you can tell me what you want for your child. I personally want my children to grow up liking the people that they are, feeling self-assured, and having the intellectual and educational opportunities that will enable them to cope adequately with society. Above all, I hope that they will be compassionate individuals concerned not only with self, but with others about them. They can do this only if they grow up to know and to like the people that they are. An educational system has a responsibility to provide an opportunity for this kind of growth that assures intellectual, social, and emotional development. As a citizen and as a member of this democracy, you are entitled to demand that your school and your society provides the best for every child. A demand of this kind, of course, means that you as a parent have a tremendous responsibility to provide a family that can nurture the child in these same pursuits - - intellectual, social, and emotional. The advent of the handicapped member in a family can be an opportunity or a liability. Which is it for the children you work with?

THE LEARNING PROCESS IN THE EARLY YEARS

BY: ELIZABETH S. FRIEDUS
EDUCATIONAL DIRECTOR
GATEWAY SCHOOL OF NEW YORK

I am happy about the subject "The Learning Process in the Early Years" because it brings attention to a process rather than to a particular handicap or method, a process that can be most clearly observed during the early years. Only when we have become familiar with the ways in which babies and young children figure out for themselves what they need to know about themselves and about their world and how to deal with it, only then can we look intelligently at the child who is handicapped by imperfect equipment for survival. Only then can we select intelligently from a repetoire of methods and materials those which can best serve a particular need. Especially important is an understanding of the very beginning of life when the foundation for all future development is being established.

Immediately after conception, the two cells which have united begin to divide. The new cells which result from division soon start to take a variety of forms in preparation for the different roles they must assume. Out of the differentiated cells, highly specialized organs are assembled, each to function in a precisely ordered relationship with every other organ in the body. An important aspect of that interrelationship is timing, so that integration of functions is assured. Any small delay, any "dropped stitch" in the organization of this complicated design can cause the entire pattern to become disrupted. When this happens, there follows a reverberating chain of reactions to the original disruption.

At birth, babies are normally provided with a group of reflexes that initiate activities basic to learning. Since learning is cumulative, the earliest stages are extremely important as the foundation for all that follows. For example, if a newborn baby doesn't start to breathe spontaneously, a quick slap results in the desired reflex. Breath is drawn in and expelled through the vocal chords. A by-product of this experience is the beginning of communication through voice, to be refined much later into spoken words organized into language. If all is normal, when the infant is only a few hours old, he produces the sucking and swallowing movements that must now bring food into his body. These movements also serve to develop skills for dealing with solid foods as well as for the eventual production of speech. The stimulation of either a bright light or a loud noise causes the infant to turn toward it, thus preparing him to gather sensory information from his environment. When his head is turned to either side, the arm on that side stretches out, bringing a hand and fingers into sharp focus. He will soon begin to listen and to look so that he may learn.

These earliest experiences start the ball rolling for learning. Sensory stimulation activates an effort to locate the stimulus and to grasp it with eyes, ears or mouth, so it can be focused upon. Soon the hands, too, will learn to grasp, to bring closer the object to be studied. The information gathering senses begin to learn how to pool their discoveries so that what eyes and hands, or eyes and ears, or eyes and mouth have learned together can be recalled by one sense alone. The mere sight of the bottle or the sound of mother's voice in the next room is enough to stimulate salivation and excitement.

Connections begin to be made. Movements become less random. The older baby, sitting in his highchair, inadvertantly drops his spoon over the side. He hears a clatter and looks for its source. The spoon is no longer in his hand. It is down there, where the sound came from. Before long, he is wise enough to hold the spoon over the side and blink before letting go, secure in what to expect. One day he will drop a soft toy overboard, anticipating a loud clatter. If he has learned the previous lessons well, he will be interested in the new turn of events, investigate it and thus add to his store of worldly knowledge. He will also want to watch for other sounds and their sources so he can produce desired effects at will. Every new experience provides some preparation for future learning and behavior. The more clearly the experience is stored, the more readily can it be drawn upon for the solution of some future problem.

While the gathering, sorting and storing of information has been going on, the whole body is preparing to organize itself for locomotion, the better to study and respond to whatever is more than an arm's length away. Efforts to roll over from back to belly finally succeed and the baby can raise his head to survey the landscape for a moment at a time. With the expanded horizon that the new posture offers, there is motivation to reach more and more distant objects. The arms stiffen with excitement, the hands push down hard and the upper body gains experience in holding itself erect against the pull of gravity. In his attempts to move forward from this position, the baby soon finds himself rocking back and forth on hands and knees. An unexpectedly vigorous push with one hand brings him into a sitting position for only a moment, until he finds himself on his back again, surprised but undaunted. There is a great deal of roly-poly experimentation throughout this exciting period, with each experience building in readiness for the next, each helping the baby learn something new about how his body organizes itself for balance and movement. The upper and lower halves learn how to work in support of each other, then the two sides, then the four quadrants, through efforts to sit, crawl stand upright and finally to walk without support.

All of this had to be self taught during the most intensive learning time in a person's life. Much more will be self taught as the baby grows into childhood. He will become adept at interpreting and responding to messages from both himself and his environment. He will learn that there can be more than one possible way to deal with a problem and that he can choose among alternatives, weighing the consequences of each in advance. We adults cannot pour this kind of learning into young children. We can, however, arrange situations in which it becomes possible for them to teach themselves.

Help is needed for the child who has suffered early developmental disruption. It may be that sensory awareness and discrimination have lagged, and therefore require intensive stimulation, or that intersensory experience need to be focused upon as a basis for perceptual development, or that body organization must be taken back to primitive levels to be built up step by step, or that the ability to evaluate the results of his efforts needs to be structured for him so he can learn from experience. There are many possible gaps in a child's ability to teach himself, gaps which he reveals to us if we observe his approach to different kinds of situations.

Some of his handicaps may be irreversible, but we may be able to diminish their damaging impact upon the total personality. Some may be remedied, entirely or in part, to help him move in the direction of independent adulthood. Sometimes detours or compensatory patterns become necessary.

If our goal for a child is the establishment of learning patterns that are as effective as possible for him, and if normal patterns are thoroughly understood in relation to their place in the total design, then we will never be guilty of rushing a child prematurely into academic learning, of by passing readiness stages, or of trying to build on a hollow core of insufficient preparation for what we wish to have him learn.

It is not essential that we determine in advance what the expected ceiling for a given child's intellectual development might be. It is essential that we stengthen gaps that are found at the lowest levels, so that every opportunity for self teaching, for independent learning becomes available. Such an approach is bound to result in pleasant surprises.

CURRICULUM AND EVALUATION DEVELOPMENT
AS A PROCESS FOR LEARNING

BY: BERTA RAFAEL
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At cost of repetition I must state that "behavioral statements" are nothing more than an attempt to clarify and specify what it is exactly that you wish to happen, with your intervention or with parent intervention or that of therapists. Multi-handicapped children need continuous intervention to reach the best of their potential. They cannot do this alone. But even more than striving immediately toward maximal functioning of a child, let us be modest and first work on prevention of secondary and tertiary deficits which surely can be avoided with the aid of a good program.

My job today is to show you in conceptual as well as in concrete (video) terms what I mean by this intervention, with the dual purpose of:

1. Working toward the child's reaching his as yet unknown maximal potential.

2. Preventing secondary deficits.

Our first concern is to get some sound understanding of the child's baseline functioning. That is, to find out what he can do, how he thinks, what skills he has when he enters your program and how he learns. In other words, to find his developmental status. I will state here emphatically that I do not believe that there is any one method of doing this. I believe it takes several weeks of careful and systematic observation. (I also believe, every child can learn something).

Let me give you some reasons for this. The variables we encounter when a child, especially a very young child, which is what a pre-schooler is, are manifold.

The child may feel unhappy leaving his family, especially his mother; he may have a separation problem. Or for that matter, his mother may not really entrust him into the care of the institution or the teacher - you.

We may be encountering what I call the "headstart syndrome." That is: If a child lives in impoverished circumstances many stimulating experiences may be missing in his environment.

We may have to deal with a child and his family for whom English is a second language.

We may have a mother who from ignorance and fear does not leave her neighborhood.

We may deal with a situation where the family is so filled with guilt feelings that we have to help them see their child in a realistic light before we can affect the child's development to any degree.

And of course - and this is something of which all of you are aware for this is not limited to inner city families as are some of the variables mentioned above - the family's feelings toward a handicapped child which manifest themselves in a variety of ways, such as overprotection on the one extreme and neglect on the other. Here you have to deal with psychological overlays which you have to clear away before you can assess a child's potential.

What do we do to get this baseline I mentioned before?

We have developed a system whereby we have arbitrarily divided the child's development into a number of areas. "We differentiate in order to unify," as Mrs. Friedus told us.

We have then divided these areas into a number of components which you see on this chart. (Chart is attached).

I am beginning to label it, THE UNITED CEREBRAL PALSY PROGRESS CHART.

First, the baseline, which is a composite of medical reports, psychometric and psychological reports, teacher observations, physical therapy, occupational therapy and speech therapy reports. This baseline requires at least a month of observation before it can be written.

As soon as we have a clear picture of a child we look at long term goals for him. These may include self-help skills, toilet training, entrance into a public school class suitable for him, and others.

Then we address ourselves to the short term goals and suggested strategies to reach them. The term strategy includes methods and procedures. In case you are not clear about what we mean by this, it is the curriculum for each child. This curriculum is a composite of all recommendations of the team members who are part of the child's environment and of this project. It may be that we have an opthalmological report which would be part of the child's basic information, but the method of positioning him once we know what his problem is becomes our responsibility. This is usually a composite of physical therapist and teacher decision.

Lastly, we write two columns of results. The first is subjective. It tells whether a goal has been achieved at the next writing period, whether progress has been made toward it, or whether it has not been achieved. Then, in the latter case we have to look at the goal and the strategies. You see, that as well as an evaluation and organization tool, we have here a viable way of looking at a child's progress and to evaluate ourselves as a team. Maybe we were right on mark. Maybe we were wrong in evaluation, in methods or strategies. So this becomes a self-evaluation tool for the staff as well.

The final column is the one we are still struggling with. Formally, we have at present achieved only a few realistic measurements: Psychometric reports and their interpretations, placement of the child after he leaves our program in some educational institution such as public school, and such concrete achievements as walking, toilet training, reading, etc.

Now some more about the goals and strategies, the curriculum of each child. We take each area and the team sits down to develop each. Here I should say that our team consists of teachers, the primary persons who really do most of the work with a child, as well as the psychologists, medical consultants, social workers, all the therapists who work (1) Directly with a child in the classroom or outside, at times when taking him out of a classroom does not have an adverse effect. This is an important part of our philosophical position - not to have individual therapy interfere with the child's classroom activity - and it is here that we differ from some other programs. (2) This team works with the teacher by recommending goals and strategies for each individual child which are carried out within the daily classroom program. (3) The goals and strategies are also shared with the parents during their visits to the program.

We believe that early education is a developmental approach to teaching not only concerned with subject matter, but with all the other areas described and prescribed on the chart......the emotional, social, intellectual or cognitive, physical and language development of a child. So we now have five goals and strategies developed for each child. For some of these you make task analysis, especially for skills. But you also have to take care of the social-emotional needs of a child and this is often done through group interaction. Therefore, we look at many conventional group activities such as music or storytime and free play time with water and blocks and all those many other activities that constitute a nursery or pre-school program, and we make an ACTIVITY ANALYSIS. That is, we write down what is most appropriate for each individual child within a given activity and how we must present it to him. To illustrate this, I am presenting to you a video tape which we made especially for you. What happened was that when we discussed this activity as part of the curriculum for one class that week, I asked the teacher to allow us to tape it.

What you will see is "making of vegetable soup," an activity that can go on at home as well as in class. Therefore, the tape has value for parents as well as for teachers. It is crammed full of cognitive offerings, because we believe that a child will take from a rich offering what he can absorb. It also shows how such a daily life activity can be adapted to each individual child, and here we are showing two children with severely handicapping conditions. Language development, physical skills, concepts and many other learning opportunities are enclosed in the tape. What is evident and is a basic belief is that to learn under the difficulties inherent in being a cerebral palsied person is an experience of success. Unless one believes that he can learn, that he is able to do some things well, he will not try. This is an axiom to which we all subscribe, and it is even more aniomatic for the children in our care.

Following the soup making and eating, the teachers prepared a lotto which in a symbolic form picks up the learnings which had been offered, and as you will see, each child's lotto card presents a different level of competence. The lotto then becomes a measure for the teacher, an evaluation tool to see what and how much each child has learned.

As time is short, this tape as well as several others will be available to you for viewing at other times as well, and if you wish, also for discussion after this presentation.

To sum up and restate what I wished to share with you today:

1. Evaluation has to be a process in which all available disciplines and all available staff skills are involved.
2. Evaluation takes time and cannot be made quickly.
3. Based on knowledge of child development, each curriculum has to be individualized.
4. Early childhood methods and procedures are our basic means for the education of handicapped children, but they have to be adapted to each individual child's physical and other handicaps.
5. Evaluation is part of the teaching-learning process and cannot be separated effectively from this process - one is dependent on feedback from the other.
6. Children learn best when their classroom experiences are making them feel they are successful, worthwhile, respected human beings.

WHAT IS ACCOUNTABILITY IN EARLY CHILDHOOD EDUCATION?

BY: FRANCES G. BERKO
EXECUTIVE DIRECTOR
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For the past eight years in United Cerebral Palsy, every staff training session has impressed upon us the need for "accountability." Evidently, the term "accountability" lacked precise clarity. Within the past two years, many groups have held workshops to train their members in the application of the various phases defined by government. Several factors now seem obvious:

1. No longer can we expect funding in grants, governmental fees or local community support unless we give clear definition of purposes, goals and strategies of programming. We must also learn to evaluate our effectiveness in realizing these pre-stated goals.

2. While the terminology may be new, the concepts have been with us for as long as there have been good teachers educating children.

3. Since we have failed to define our "accountability," others are doing it for us. Criteria are emerging which now seem impossible. Do not ignore them. If we try, someday we may have the knowledge and the strategies to meet these criteria through better education of our children. In the interim, greater realism may be developed through this attempt.

Phase I of any program is always evaluation - that is, teacher evaluation of the children under her charge. Two examples of such evaluations are being distributed at this meeting.

Phase II, done simultaneously with Phase I, is the establishment of the Levels of Competency for the program - what skills will be developed for each child by the pre-school program. These competencies have been described in a preliminary draft of the Basic Program Plan of the National Program in Early Childhood Education as:

I. The development of intellectual competence that will permit all children freedom of choice in determining their styles of environmental adaptation.

The acquisition of this competence assumes that there is clarity in definition of the cognitive demands of the various experiences and tasks offered to children in pre-school programs.

II. Of equal importance - the development of language competence -

The comprehension and use of verbal signals including the manner and mode of language development and the effect of deprivation, whether physical, mental, emotional and/or environmental, on the acquisition and maintenance of language.

III. The development of social and interpersonal competence.

The basis of this competence may be found in the answers to the following questions:

a. What constitutes the earliest effective social stimuli and how do they become the basis for subsequent social learning capabilities?

b. How do social control skills develop?

c. How are initial transitions between the home and the pre-school setting made without undue stress?

d. How does the young child come to form effectively rewarding relationships?

e. How do children develop a sensitivity to the needs and well-being in other people?

f. How do children gain a genuine appreciation for the diversity in other people?

g. How does the child gain the ability to acquire and internalize culturally appropriate standards of behavior?

h. How does the child learn to make realistic judgements concerning the various kinds of risk-taking in social settings?

IV. The development of motivational and attitudinal competency.

This includes:

a. Self-concepts as intellectually and socially competent.

b. Self-concepts as having secure roles positions, status, group membership and minimal identity.

c. Willingness to explore, investigate, prod, test new situations, both on one's own initiative and in collaboration with the group.

d. A value of knowing things - usefulness of knowing how to do things - satisfaction in showing and teaching others what you know.

e. Internal standards for juding appropriateness of own and others behavior in various contexts.

f. Habits of learning and thinking that are at least minimally responsive to the demands of the task at hand.

g. Some realistic balance between persistence and determination and a willingness to compromise before the persistence becomes self-defeating.

h. Some primitive ability to empathize with others.

i. Ability to take success in stride and deal constructively with failure and frustration - and ability to safely vent, clearly communicate, and positively learn from one's own emotions.

Phase III is the process of combining where the child is (Phase I) with where he ought to be when he leaves your program. This program development occurs in series of well defined stages:

Stage 1: For each child, the following questions may be asked:

1. List everything the child can do in specific behavioral terms, i.e., Can he button his coat? Can he hold a pencil? What simple concrete commands can he follow? How does he communicate that he has to go to the bathroom?
2. List in behavioral terms those functions of the child which are most disruptive to you. List in order of priority which behaviors you would like to extinguish first.
3. List the ways in which you will facilitate change in those behaviors which are disruptive to you.
4. List the items from #3 which meet needs of the majority of the children in your class.
5. List the specific disruptive behaviors that you will be programming for simultaneously with #4 for those children who are not included in #4.
6. List in behavioral terms the competencies of each child. List in order or priority which need strengthening immediately.
7. List the strategies you will use to strengthen each of these competencies.
8. List the items from #7 which ones meet the needs of the majority of the children in your class.
9. List the specific strategies that you will be programming for simultaneous with #8 for those children who are not included in #8.
10. Demonstrate how you will set up a curriculum:
    a. in terms of the classroom group.
    b. in terms of the individual child.

Stage 2: Having done this, you are now ready to set forth your Major Goals at the child's present level of function, the Minor Goals established to achieve each Major Goal, and the Processes to be used in achieving each Minor Goal.

Process: What are you going to do concretely to facilitiate the child's improvement in each specific function with which you are concerned in a specific period of time - and how much time do you estimate spending on each concrete strategy?

Minor Goals: What specific functions will be gained by the child in the stated discrete time period, i.e., the next month?

Major Goals: What is the overall purpose in the total life function of the child of the stated minor goals? What level of competency will be achieved through each of the minor goals?

Stage 3: The establishment of Behavioral Objectives is a natural outgrowth of Stage 2. To some, Behavioral Objectives, as they are now being considered by the New York State Department of Education, seem both unnecessary and self-defeating, provided that the Goals and Processes of Stage 2 are clearly stated. What is a Behavioral Objective? It is a statement which answers the following questions.

1. What is to be accomplished?
2. By whom?
3. When or for how long?
4. Under what conditions?
5. With what tools or materials?
6. To what extent or degree of accuracy?
7. Judged how?
8. Any special features?

These then are some of the elements of accountability in program development for early childhood education of multiply handicapped children. It cannot be over-emphasized that the very existence of your program, as well as your own competencies as a teacher, may, in the future, rest with your proficiency in such program accountability.

CURRICULUM DEVELOPMENT - PROFESSIONAL ACCOUNTABILITY

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Frances Berko just gave us an excellent overview of the process of structuring a dynamic curriculum based on the individual needs of the child. In addition to this, I feel that we need to explore together some philosophical implications.

While doing research for this presentation, I went back to some of the basic texts on curriculum development. One of them, Modern Elementary Curriculum by Dr. William Ragan, defines curriculum as, "All those experiences for children for which the school accepts responsibility." So it's very simply defined for us as all of those life experiences of the child with which we are involved. Fran gave us the tools and a way to analyze all of those life experiences. To further illustrate and define curriculum - I would like to share with you a fable about how a group of animals once started a school and how they developed their curriculum:

> Once upon a time, the animals decided they must do something heroic to meet the problems of "a new world." So they organized a school.
>
> They adopted an activity curriculum consisting of running, climbing, swimming, and flying. To make it easier to administer the curriculum, all the animals took all the subjects.
>
> The duck was excellent in swimming, in fact better than his instructor; but he made only passing grades in flying and was very poor in running. Since he was slow in running, he had to stay after school and also drop swimming in order to practice running. This was kept up until his web feet were badly worn and he was only average in swimming. But average was acceptable in school so nobody worried about that except the duck.
>
> The rabbit started at the top of the class in running, but had a nervous breakdown because of so much make-up work in swimming.
>
> The squirrel was excellent in climbing until he developed frustration in the flying class where his teacher made him start from the ground up instead of from the treetop down. He also developed "charlie horses" from overexertion and then got C in climbing and D in running.
>
> The eagle was a problem child and was disciplined severely. In the climbing class he beat all the others to the top of the tree, but insisted on using his own way to get there.
>
> At the end of the year, an abnormal eel that could swim exceedingly well, and also run, climb, and fly a little, had the highest average and was valedictorian.

The prairie dogs stayed out of school and fought the tax levy because the administration would not add digging and burrowing to the curriculum. They apprenticed their child to a badget and later joined the groundhogs and gophers to start a successful private school.

Does this fable have a moral?

I think this fable has some implications for all of us who have assumed the responsibility for the life experiences in early childhood education. Perhaps we are joining the prairie dogs in trying to develop something new in this field.

United Cerebral Palsy Associations, Inc., was fortunate in obtaining a grant from the Bureau of Education for the Handicapped in which we are trying to distill from 5 infant centers throughout the United States the exemplary parts of their programs, to develop a curriculum guide for infants, to develop a staff training curriculum, and a model or models for other parents to use. The infant center staffs are all going through the process that Fran described for us. They have been struggling with these behavioral objectives and competencies because they recognize the importance of this.

In the group of the substantially handicapped, it is more than just the school, more than just the teacher involved. We have a whole team which includes everyone and everything that's happening in the experiences of these children. Consequently, in developing the curriculum we must include the occupational therapist, speech therapist, physical therapist, nurse, physician, psychologist, social worker and everyone else, but most particularly, the parent.

The infant and the young child are with the family many more hours than he is with any of us. There are many ways that this kind of service can be delivered, and I think that it is uniquely done in these 5 infant centers. I am equally sure that there are people in the audience who have methods of delivering this kind of service which are probably just as exemplary. We will be sharing these methods later in small groups throughout the Conference.

In some centers, the infant may come with the mother on a monthly basis, and the therapist teaches the mother what to do in the home. In other centers, the infants' mothers come as a group and in still other centers, the infants stay for the whole morning. The grouping of these infants and their families is quite different in all 5 of our centers. One is even a residential program. At any rate, one of the uniquenesses common to all these centers is that all of the staffs are involved in developing a curriculum. Another uniqueness is their easy role exchange and recognition that everyone is a teacher regardless of their individual professional training. The parent and even the infant become teachers at times.

The population itself which represents the environmental need for these programs presents us with problems. However, throughout all of our centers, with their different kinds of groupings and different kinds of children, sometimes their conditions will be undiagnosed--it may be to our advantage because I feel that people in special education particularly are guilty of dwelling on the diagnostic categories which lead to a negative expectancy attitude where the learner is doomed to failure.

Because we've learned about all the things these children cannot do because of their disabilities, we do not expect them to be successful.

To illustrate the positive aspects of expectancy, I would like to share with you a visit I made to a small private college in St. Louis where the chairman of the Physical Education Department had developed a course for college students which used pre-school children from our affiliate in St. Louis. She had devised this course which is entitled, "Adventures in Learning", and had asked us to come to observe and evaluate it. I am sure I learned a great deal more than she did.

Note that this woman is not a trained special educator, but she developed a program using whatever resources were available to her, using the tools within her immediate grasp and utilizing all of the competencies that she possessed. The course was designed to give these pre-school, multi-handicapped children some experiences in physical education. Coupled with these experiences, the handicapped group received, the college girls taking the course worked in teams of two in providing meaningful learning activities for the children. They were a young, energetic, and enthusiastic group who were majoring in special education, physical therapy, or speech therapy. They were learning to exchange their roles while working on behavior of the children in a physical educational setting.

The children were greeted by the girls as they arrived and an active rhythm and music period started the day. A parade was organized which led to the pool. The children were delighted with this experience and any fear or anxiety concerning the swimming pool or water was not observed. The physical education chairman developed cork floats which were cut in the shapes of circles, squares and triangles painted in primary colors. While in the swimming pool the children were discriminating and matching the various colors and shapes, using many alternatives which emphasized cognitive aspects, especially focusing, attending and information processing skills. The chairman encouraged her students to present these alternatives and use an immediate reinforcer for the children.

After the swimming program, the children participated in some simple, elementary calisthenics on an individual basis. After these exercises, an obstacle course had been set up in the gymnasium. One of the most interesting features about this was the use of homemade, large cut-outs of circles, rectangles and triangles. The children would crawl through these various shapes, then used inserts of the same shape they had just crawled through, in order to enhance their information processing skills.

One of the mothers commented that her little boy had said, on the way to the school that morning, the name of the college, which is Fontbonne. It was the first thing her child had ever said. If this is any evidence of success, then we know that his experiences had been internalized and some of the barriers to learning had been overcome. The curriculum was meeting his needs.

We always have to assess the needs of the child before we get into any kind of curriculum development, and in this group, assessment and evaluation are built into the program by allowing time to plan and evaluate the effectiveness of the physical education activities. Fran also mentioned goals. I firmly believe that one of the problems in developing a curriculum is that the agency itself has its goals, each staff member has his goals, and the parents have their goals; the community and the profession have their goals, and sometimes, the children have their own goals. Somewhere these goals all have to be interfaced so that whatever the child is doing within the program - that environmental event, that activity which is planned, reflect such interfacing of goals. The curriculum is not successful unless it meets these goals, whether we call them behavioral objectives, specific course strategies, purposes, etc. It is the thing we are trying to accomplish. The problem arises because all these different people and agencies have goals that aren't expressed which have to be recognized in order to have an effective program. The individual intervening with the child and family may have an unexpressed goal which is interfering with meeting the expressed goals of the agency. On the other hand, sometimes the agency has unexpressed goals which are in conflict with the staff. In the process of curriculum development, a period of time must be set aside where these goals are brought out into the arena, so that they may be discussed in an objective way.

There are some concerns about infant programs which must be mentioned. Sometimes the programs are labeled infant stimulation. Some caution should be exercised here and a brief mention of the works of Strauss and Lehtinen, which heavily emphasizes the distractibility aspects of brain injury in the ensuing confusion that too much stimulation may present. Keen assessment of the infants is most essential. I purposely wore this shirt today, with all of its multi-visual patterns to illustrate the confusion that could arise in infants who have a perceptual problem. With other kinds of children it might be a very good stimulus. Again, we have to know what kind of children are in our programs and we have to know them very well, because barriers to their learning may be presented rather than overcome. Unless we have the insight, unless we have the tools, the staff, knowledge, and skills about what kinds of infants and children with whom we are dealing, we may be presenting barriers to their learning. Another area with which I am concerned is that of not allowing enough time for the infants to explore and experience the environment, and particularly, experience the consequences of their exploration. Often times, our daily scheduling actually interferes with the child's learning because we allow 10 minutes for cognitive development and 20 minutes for PT, etc. This implies, of course, a cross disciplinary approach which I will only mention here since Mrs. Haynes will go into this approach in depth later in the morning. Many of these severely disabled children are still being removed from a learning environment to have some kind of therapy in a separate room. This totally negates everything we have learned about what does not work. If everybody worked together in concert with their interventions with the child, we would not be interrupting the learning experiences of these children.

One of the most exciting things, on which I am sure everybody could make their own improvements, is part of the curriculum at UCLA Infant Program. It is called, "The Sensory Story." A report of it is published in Developmental Medicine and Child Neurology, 1967, by Dr. Margaret Jones and Mary Barrett. The child is brought into the room (two or three children could also be presented with this story). The story is illustrated with concrete objects which are multi-sensory in their stimulation. The child's name is used for motivation purposes. For example:

> Sally was sound asleep.
> "Hi, Sally, it's time to get up."
> A soft red blanket covered Sally.
> Sally rubbed her hand on the soft blanket. The blanket felt soft and smooth.
> On the floor was a rug. The rug was soft and bumpy.
> Sally rubbed her hand on the soft, bumpy rug.
> Mummy gave Sally her pink brush. The brush was stiff and hard.
> Sally brushed her hair with the stiff hard brush.
> After breakfast, Sally played outside.
> Sally played with the ball.
> The ball was round and smooth.
> Sally rolled the ball on the ground.
> She found another ball.
> The ball was round and sharp.
> Sally played in the sand. The sand was dry.
> Sally wanted to make a sand cake.
> Sally poured water into the sand.
> Splash, splash went the water in the sand. The sand was wet.
> Sally took the wet sand in her hand.
> She made a wet sand cake.
> Mummy called, "Sally, come help me get dinner ready for Daddy."
> Mummy helped Sally wash her hands.
> The wash cloth was wet and hot.
> Mummy gave Sally a cold ice cube. Sally put the cold ice cube in Daddy's glass.
> The ice cube was wet and cold.
> Sally heard something outside.
> What did Sally hear?
> Sally opened the door.
> She saw Daddy in his car.
> Daddy honked his horn to Sally.
> "Hi Daddy. Dinner's ready."

The blanket and other objects mentioned in the story would be presented to the child. Certainly everybody could adapt and utilize this kind of information which is readily available in the literature. It is almost redundant to point out the value of this kind of approach to learning and curriculum development. The information processing skills are self-evident in this story.

In conclusion, I would like to share with you an experience which has given me sustenance over the years. As a young college student, I attended a lecture given by Mortimer Adler, who is the founder of the great books theory in education. He likened the intelligence capacity to varying sizes of containers and lamented the fact that in all too many cases we provided cream for the largest containers and only skim milk for the half-pint containers. It is up to us to provide our substantially handicapped children with the utmost quality of interventions, so that we do put cream into even the smallest container.

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PROBLEMS OF ACCOUNTABILITY IN CURRICULUM DEVELOPMENT FOR EARLY CHILDHOOD EDUCATION OF THE HANDICAPPED

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I have been asked to speak about the topic of accountability, as it relates to the development of curriculum materials, methods, and procedures in the field of early childhood education for the handicapped. I have taken the liberty to define accountability in terms of the evaluation components which are more and more frequently being asked for in our field. Curriculum accountability translates into questions such as: How effective is our program? How much change occured in a child or a parent during this school year? Do we know a more effective way to produce greater learning in these young children? If we plug in component A in the existing curriculum, will the learning increase or decrease, or perhaps stay the same? Which children can learn most effectively using one set of materials and which can and will learn most effectively using a different set of materials?

The above questions are some of the concerns which I have been dealing with at United Cerebral Palsy of Queens for approximately the last three years. As a private, non-profit agency, United Cerebral Palsy of Queens has run a pre-school program for crippled children which dates back at least five years. This pre-school program is called the Young Infant Program. It was initiated under a demonstration grant from the Association for the Aid of Crippled Children, as a program designed to provide educational experience for young cerebral palsied children, and counseling for the parents of these children. The children in this program may be as young as ten to twelve months, and as old as a regular kindergarten child, depending on the functional level of the child.

The program, in brief, is structured in the following manner. Children are grouped according to developmental level, from eight to twelve in a group. One group attends in the mornings, on Monday, Wednesday, and Friday, while another group attends on Tuesday and Thursday. There is an afternoon program of older children also. Parents must bring the children to the program and while the children are in "school", the parents meet for group therapy. The parents also participate as teacher aides. There are approximately thirty children in this program, and it has been my role to evaluate certain parts of the program, especially in terms of some of the questions which I posed earlier.

Our experiences with these children attest to the tremendous difficulty of measuring growth in these young infants. It is difficult enough to find the appropriate materials and activities for these young handicapped children. It seems almost an impossible task to construct a curriculum which can be put down on paper and shared with others working in this field. In part, we have done this in the past two years, and I would like to describe several of the difficulties we encountered as we tried to evaluate what we were doing.

One large, seemingly insurmountable problem faced us as we began to evaluate our program. Research is usually defined in terms of experimental and control groups, moderately large samples or numbers of children, experimental modification of procedures under controlled conditions, randomization of subjects or treatments, as well as levels of significance, statistical tests, or computerized analysis of data. Research demands the testing of hypotheses which have been established prior to the beginning of a program. In short, research involving people, or in this case children, is more often than not a very difficult proposition to carry on at a sophisticated level without abrogating the rights of the people involved or the experimental conditions as they are established.

For example, parents object ever more strongly to the idea of "experimentation" with their own children, and parents are becoming more sophisticated about research programs. It is becoming more and more difficult to convince parents that the researcher who is asking all those involved questions is "objective" and concerned with the "good" of the child. At times, other parents find out about new or innovative programs, and ask questions as to why their child cannot be included in the program, and the response that their child is one of a control group does not always satisfy the parents.

It would be my judgement that it is not always necessary to participate in research. Very often, programs are not large enough, or well enough staffed to make research activity worth the time and effort. At the same time, a sincere and operative program of evaluation is, in my opinion, essential.

I would define evaluation, as opposed to research, as the structured monitoring of your program. It is in this area that accountability can be achieved for all programs, large or small. Evaluation provides a periodic assessment of what is going on in your program, and consequently, of what impact a curricular change has on the children. It also serves to make your staff more observant of the growth or change in the children. An adequately structured evaluation component gives the teacher, as well as the administrator, the feedback of information which is necessary for the ultimate goal of your curricular process; which is the building of new components into your program which will help assure that your program is meeting the needs of the children as their needs change.

Evaluation, as an ongoing process is a requirement of any program of curriculum development. It demands the skills of collecting data, observing change, yet at times does not demand the rigors of experimental conditions. To evaluate a class of six crippled pre-schoolers is legitimate. To attempt to conduct a research study of the effects of a new curriculum by pairing, or randomly assigning three children into two groups, or two children each into three groups, serves no purpose. The evidence is not strong enough, the statistical procedures not powerful enough when we deal with these small groups.

Let me move on to the second major problem of curriculum development in this area of early childhood education for the handicapped child. The second problem pertains to the disability. In this regard, I see two major sub-problems, the kind of disability, and the relation to the learning process.

For example, we recently had a pair of separated siamese twins in our Young Infant Program. They had undergone surgery at the Institute for Rehabilitation Medicine in New York City and came to us at an age of 42 months. Each twin had been given a full trunk and one leg. They were very mobile, ready for preschool experiences and participated very well in our program. They tested out to be in the normal developmental range. After a year in our program, the parents moved out of the Queens area and the children no longer attended our school.

The point I am driving at is this. These two children represented a very unique kind of disability. At the same time, in terms of their learning ability, they very closely approximated the "normal" child if adaptations were made for their physical deficit. The curriculum program which we developed for them had specific modifications, yet had a tremendous amount of normal pre-school activities in it.

The kinds of disability we are dealing with present an almost unending complexity. For example, is our new curriculum appropriate for one specific disability and not any others? If we evaluate a specific curriculum which involves perceptual training as excellent for a set of brain-injured and crippled children, does it follow that it should be applied to other crippled children as well? Or are we constantly designing and implementing a series of individualized curricula, of which there is no end, and possibly no future replication or appropriate application to another set of children? Do we have to tackle the problem of an appropriate curriculum for a left hemiplegia, as opposed to an appropriate curriculum for a right hemiplegia? I feel, at this point, that it is critical to find common elements, or we will spend the next fifty years writing individualized curricula.

The relationship between the disability and the learning process also raises some critical questions at this point. I will grant the fact that crippling conditions restrict the physical mobility of the children in our programs. I will grant the fact that the crippling conditions are often paired with speech impediments, or mental retardation to one degree or another. I will grant the fact that physical disability often has associated with it problems of perception, or problems of body-image, or self concept, or problems in dealing with interpersonal situations.

What has not been explored as exhaustively in our field is the degree to which the learning process adapts to these disabilities, or the degree to which the child needs no special curriculum. In many instances, the fact of a disability is actually a Non-Problem, in that it is irrelevant to the learning process. Children in any program, to some degree, learn about themselves and the world they will live in, in exactly the same way that other children do.

Obviously, the question to be answered is - to what degree does that hold true, and in what areas is it critical to provide a separate and more appropriate curriculum for handicapped children.

The third major problem of curriculum development is the issue of intuitive response, versus observable data. Given a large enough group so that research can be carried on, we still face the test of which data to collect, and why we collect it. If we decide to monitor the growth, say in language development, we almost certainly reduce the degree to which we observe and monitor in any of a number of other areas, such as physical growth, social growth, perceptual growth, or intellectual growth. Choose the area you wish to focus on and you lose depth perception in another area.

In addition to this, there is a basic disagreement between the skills of many teachers as opposed to researchers. To a parent or a teacher, growth which is important may be a slight change in feeling. To a researcher, nuances have to be translated into statistical data, and very often, either this cannot be done, or as the saying goes, much is lost in the translation.

In the program at United Cerebral Palsy of Queens, we have always attempted to build into the ongoing program an evaluation of the day-to-day activities. At times, this was done informally by lunch time conferences with all the staff involved. At other times, it was done by daily reporting from each member of the staff, using observational schedules. These schedules attempted to direct the staff's attention to both the areas of greatest success, as well as the largest problem that a child presented in any one session. The staff soon learned to do this well; the problem arose when the reports had to be quantified.

Data which a researcher wants very often deals with performance; how often did the child exhibit hyperactive behavior in this two hour period? Was it:
a) never b) sometimes c) often d) constantly. The teacher's response to this kind of quantification of behavior is exactly as noted above, if she agrees to fill out the forms, she does so with the reluctant premonition that the "quality" of growth in a child was left out of the statistical reporting.

The final problem I would like to discuss is the problem of prediction. If a curriculum is to be developed, it has to be standardized to the extent that valid predictions can be made from it. For example, it has to be able to assure us that what is included in the first month is really necessary for something which comes later on in the program. An earlier learned skill leads to a later demand for more sophisticated learning. Perceptual training theoretically leads to more successful instruction in reading. The part of the curriculum covered in September and October should be the building blocks for what is covered later, whether it is in November or next year.

For example, we use certain instruments for each of the children in the program. The teachers, as well as the parents, both respond to a Vineland Social Maturity Scale. We have had to develop modifications in the scoring of this instrument. We also use the Bayley Scales of Infant Development from the Psychological Corporation, and a Communication Behavior Scale which was developed by the Shield of David.

We have begun to establish norms for the children in our program for each of these instruments. In the near future, it will be possible to combine these sets of data, study the relationship between growth in one area and growth in another area, and by using regression formulas, begin to predict for any child a reasonable expectation of his or her performance in our program.

Prediction is a very difficult facet to build into a curriculum. It has been partly possible to build it into such things as intelligence tests, tests of achievement, and many other forms of testing presently used in the schools. Yet we continue, and rightly so, to believe in the principle of prediction. It is one of the tests of relevancy of a curriculum.

Prediction is a complex process. While the media seems to have been able to break down voting patterns to the point where they can predict accurately with ten percent of the returns, education is not yet as capable. Research statisticians tell us that the problem of prediction has two major factors, the accuracy of the data, and the comprehensiveness of the data. How accurate are the child's test scores, and how many test scores do you have on any one child, or how many children have you tested using this curriculum? If you are going to make claims for a particular curriculum, how complex or extensive are the elements in it? The more complex the curriculum, the greater the predictive power to it, in terms of juding future success or failure of the child in any of many situations.

Having developed some of the problems in curriculum evaluation, let me turn to some of the possible solutions to these problems.

The problem of research versus evaluation has already been discussed in terms of some ways of handling this. Evaluation on a pre and post basis will give any program some partial data, from which conclusions can be drawn and, more importantly, some rather critical questions can be raised about what is going on from day to day. I am not suggesting the capitulation of the teacher in the classroom to the data garnered in the evaluation process. I am not suggesting that the teacher be rated or evaluated personally as a good or bad teacher on this data. I am suggesting that periodic, if only at the beginning and end of the year, data collection will provide useful evaluative material. Perhaps better than a pre and post evaluation is a year-to-year evaluation, where the child is tested one spring and then again the next spring.

Periodic data collection also leads to the concept of longitudinal growth evaluation. It may be as important to keep records of the progress Billy made this year as opposed to the progress he made last year. In terms of evaluating a curriculum, it may be important to see how one group responded to the program one year, and compare that group with the group the year before.

There are some statistical means of handling this problem of small group evaluations. They do not prove causality, but they can be used to test for significant differences from, say one small group one year to the same group the following year, or between two different groups, if certain information is known about these groups.

This statistical technique is called, "Analysis of Co-Variance" and is designed to measure differences between groups that are known or are suspected to be different. Analysis of co-variance takes the initial differences between groups into account and allows the comparison of these different groups.

The second problem of the disability factor requires a more complex treatment of the data. To discern what is important, relevant, or critical in the relationship between a disability and the child's progress in a particular curriculum demands several steps.

To make a judgement about the many complex elements of a curriculum and how these elements relate to a particular type of disability, the evaluator must first collect data on as many different aspects of the curriculum as possible, and also collect as much data about the child as is possible. There is a statistical test which measures the degree of interrelatedness between varying elements. It is Factor Analysis. Given a set of curriculum experiences and judgements from teachers about the value of each piece of the curriculum, we can construct statistically the most central core of the curriculum through Factor Analysis. If the elements of a child's disability are included in the data, we can relate critical elements in a curriculum to the specific disabilities of any particular child.

The third problem of empathic responses versus observable data must be solved through a blending of research, and teaching skills. It can only be done through the training of these staff members to be responsive to the disciplines of the other staff members. Teachers will learn to be more clinical, clinicians to be objective and, if you are lucky, researchers to be more empathic. It is only then that curricula in our field will begin to have all the elements needed to make them comprehensive and able to meet most of the needs of the children.

Finally, the problem of prediction can be attacked by several methods. It seems necessary to establish separate norms for handicapped children in some instances, and consequently to interpret the data we have collected in reference to a comparable group - other handicapped children. As a researcher, I have visions of the computers in Washington finally spewing forth normative data from all the reports which are now on file from the local projects. Until that day, it seems important to evaluate the curriculum you are using in terms of the local population, as well as the normal child if you wish.

The statistical tool which would be useful in this aspect of the power of prediction of a curriculum is Multiple Regression. If a program has been underway for at least two years, and data has been collected about the children in the program, then even a small program can establish tentative normative tables for performance under a curriculum task. Once this normative data has been established, it can be combined into relevant relationships and through a multiple regression formula, individual prediction for each child can be made in your program. At this point, the child's growth is measured against what you predict should be expected of the child. This may be the fairest of all evaluations of a curriculum.

One final word. I have suggested basically that data must be collected systematically. I have also listed some statistical techniques such as analysis of co-variance, factor analysis, and multiple regression. These are available in computer centers as programs which are already developed. You have to supply the data. More importantly, you have to train your staff to be observant of the changes they see. You have to set up on-going monitoring of your curriculum. A structured evaluation will lead to many different concepts which you may want to try, and most importantly, it basically satisfies your need to be accountable.

WHY ARE WE HERE?

BY: ELIZABETH M. GOODMAN
CHILD ADVOCACY PROGRAM OFFICER
BUREAU OF EDUCATION FOR THE HANDICAPPED
U.S. OFFICE OF EDUCATION

I am pleased to take the place of Jane Deweerd, the BEH Program Coordinator on Early Childhood, and discuss early childhood with you, one of my special interests. My role in the Bureau of Education for the Handicapped, as an education specialist, is to serve as Program Officer in the recently developed Child Advocacy Program. I am also responsible for promoting much of the service integration efforts or interagency coordination in behalf of the handicapped children. I also serve as a State Plan Officer. Before joining the Office of Education in 1966 to help implement the new federal thrust relating to education for the handicapped. I served, like yourselves, at the local level once upon a time as a special education teacher, but since the 1950's as Principal of the Sharpe Health School for Crippled and Health Impaired Children in Washington, D.C. - a kindergarten through 12 grade school. I played a major role in the planning and development of this school which became one of the nation's outstanding and model schools for the physically handicapped. About 50% of the student body enrolled in the school have cerebral palsy.

In addressing the question as to "WHY ARE WE HERE" - the subject assigned to me - I find my remarks will fall into three general categories. The first is the mission of providing an early education to handicapped children; the second relates to the development of an understanding of the role of the Bureau of Education For The Handicapped, Office of Education HEW in fulfilling this mission; the last concerns the advocacy roles for insuring the rights of the handicapped child to reach his maximum potential through full and equal educational opportunity.

The Mission: Most of us are here today, in one way or another, are dedicated to the mission of assisting handicapped children receive the best possible services during their early years of life. Based on evidence and studies, many of which have been presented to you at this conference, we have reason to believe that handicapping conditions in children must be diagnosed early in life. The child must be provided with appropriate educational experiences, along with supportive interdisciplinary services. Most of us also believe that each parent must be actively involved in the developmental and educational process of his child. If provided these services during his infant and pre-school years we believe a child's chances for lifetime functioning will be markedly improved. Early intervention, we believe, could make the difference as to whether the handicapped child spends his life in an institution or with his family within a community environment. It could make the difference as to whether some children remain confined to their own homes. (Sometimes with home instruction,teachers,and sometimes not) or attend special education classes. It could make the difference as to whether some children are integrated in classes for regular children, or remain in special classes for the handicapped. It could be a deciding factor in determining whether a person acquires vocational skills and becomes economically independent, or whether he or she becomes a financial burden. In other words, I think we believe that early education of the handicapped can be decisive as to whether or not a child, especially one severely handicapped, will function on a higher level than he otherwise would if early educational intervention were not available.

The researches on cerebral functioning tell us that the brain, if properly nurtured, could develop to about 50% of its capacity by the time a child is two years of age and to almost 100% by the time he is five. That tells us a lot about the need for active stimulation during the infant and early years. A child who is denied certain types of stimulation during this period may lose his chances for full mental development. Unfortunately many non-handicapped children have been denied adequate cerebral stimulation to insure their maximum development; however, most of these children who live within a reasonably adequate environment, will develop through the normal daily interaction with his family and peers. For children with cerebral dysfunction, it becomes necessary to improvise or stimulate much of the environmental stimulation to provide the child with visual, physical, sensory or motor experience which he could not gain for himself.

We are here today because we want to exchange experiences in providing infant and pre-school programs for the multiply handicapped; we are seeking new knowledges and skills in this field; we each want to improve our centers.

I am pleased to say the many United Cerebral Palsy affiliates have taken leadership roles in developing pilot programs for pre-school physically and multiply handicapped children. Much of the knowledge we already know in this area comes from the programs piloted by your organization. These programs have demonstrated,we now believe,that handicapped children of all degrees of severity can benefit substantially from infant and early education.

The Bureau of Education for the Handicapped: This organization, established by Congress through the 1966 amendments to the Elementary and Secondary Education Act, now administers or monitors about 14 separate programs aimed at improving the nation's capability for providing educational services to handicapped children. The authority for most of the programs are contained in the Education of the Handicapped Act, (P.L. 91-230, Title VI), some are authorized in Titles I and III of the Elementary and Secondary Education Act, (also P.L. 91-230). These programs provide the thrust for the national effort in behalf of the handicapped and include aid to States for Pre-school, Elementary, and Secondary Education. Financial support for programs for handicapped in state supported schools, grants for supplemental educational centers and services; allotments to the States for vocational education; grants for early education for the handicapped, deaf-blind centers, regional resource centers, training of personnel, research, and others.

Not everybody in education understands the process of providing federal aid to education. Some people think that the U.S. Office of Education is like a school system which provides services directly to people. This is not so. In general, the federal aid administered through the U.S. Office of Education is a system for disbursing funds for educational programs authorized by Congress. The programs are developed by agencies that are eligible to receive funds. While the ultimate beneficiaries of the programs are the handicapped children, eligible applicants for direct funding from the Office of Education are usually State Departments of Education, institutions of higher education or public and private agencies. For example, under the Program for Training Professional Personnel for the Education of the Handicapped, funds are available to institutions of higher education to establish and operate a training program of this nature and to offer scholarships or traineeships to eligible candidates for such training. The Federal Government does not offer a scholarship or fellowship directly to a student, rather a student must apply for this assistance from the university which has received a grant from the Federal Government. Thus, the federal programs, on the whole, are a way of administering funds to eligible agencies.

The U.S. Office of Education distinguished between State-Plan Programs (also known as non-discretionary programs) and discretionary programs. Funds under the State-Plan Programs are usually dispersed to the States on the basis of a formula. The States award the money on the basis of their own priorities. The Commissioner of Education dispenses funds under the discretionary programs directly to eligible agencies on the basis of his priorities.

Part B of the Education of the Handicapped Act is a State-Plan Program to provide support to the States to enable them to improve and expand the services to pre-school, elementary and secondary handicapped students attending local public schools. Children attending private schools may also benefit, but the funds and activities are under the public agency. The State Department of Education also receives funds under the Vocational Education Act, Amendment of 1968, 10% of which must be for vocational education for the handicapped.

Two other State plan programs are Title III of the Elementary and Secondary Education Act for supplemental services to handicapped children, and the Title I Elementary and Secondary Education Act Program for handicapped children who are supported by the State, usually in State or other institutions.

The Early Childhood Education Program is an example of a discretionary program. Comparatively speaking, there is very little money to dispurse under the discretionary programs. Last year's appropriation for Early Childhood for the Handicapped totalled $7 million, not too much considering the numbers of handicapped pre-school, infant and young children in need.

The Handicapped Early Childhood Education Program provides for the establishment of model programs, with funding available to an agency for three years to develop and put into operation early childhood education services. In selecting agencies to receive awards under this program, the Bureau of Education for the Handicapped is looking for projects which not only have the capability of serving as a demonstration center, but have a high potential for replicability as well as continuity after the federal funding is no longer available to this project. We call this the "multiplier" effect whereby only a small number of children benefit directly from the federal project, but large numbers of children in need ultimately benefit. For example, the Early Education Act for the Handicapped prompted the State of Texas to provide pre-school education for children beginning at age 2. Thus, many school districts in the State of Texas are now operating pre-school education programs for non-handicapped, as well as handicapped, with Federal money used for pilot demonstrations.

Commissioner Marland's indicated to you yesterday that early education is one of the priorities of the Office of Education, especially for the handicapped child. He suggested a strategy of trying to seek monies for some of these programs in cooperation with other federal programs not necessarily operating within the Office of Education. Some of the other federal programs which could be used to provide educational services to pre-school handicapped children, include the Headstart Program administered by the Office of Child Development, and the Day Care Program which is administered through the Social and Rehabilitation Services Administration.

Because the recent comprehensive child care bill was vetoed by the President, there is no overall federal legislation for pre-school children. Each state and agency must use its own ingenuity in finding resources to support such programs and utilize the existing federal programs to the utmost in behalf of services to young children.

The Headstart Program authorized under the Economic Opportunity Act is primarily aimed at 4 and 5 year old children from poverty areas. The Day Care Program is an interpertation of Title IV under the Social Security Act which provides for certain types of child care services both in and out of home. Most of the children served are recipients of aid to dependent children. The States which participate in this program use Federal funds to meet 75% of the cost of each day-care center. The local community meets the rest of the cost .

In my efforts to coordinate BEH programs with programs like Headstart and Day Care, I have been encouraging the initiation of these programs to include handicapped children in their ongoing programs, and in some instances, to set up separate programs for handicapped children. We have had some degree of success in developing these programsto serve the handicapped in the Model City areas; another federal program aided at assisting persons in areas of great need. In some communities we have coordinated the services of a BEH funded Early Childhood Center for the handicapped with a neighborhood day care center, whereby the BEH funded center provides special resources relating to education of the handicapped and makes it possible for the Day Care Program to maintain some handicapped children in the regular program. This year we will be supporting such a program in the Model City Area of Athens, Georgia. Through such a coordinated approach, a number of services can be made available to the handicapped. The BEH funded center can serve as a resource to the general day care center making it possible to include handicapped children, usually the mildly handicapped. Services that might be provided include: diagnostic services, training of teachers, teacher aides, to work comfortably with the handicapped, and some classroom support. (It devises a system whereby a resource is available for recognizing symptoms of potentially handicapped youngsters with appropriate preventative intervention applied at an early age. It is based on the theory that) Many childrenwith handicaps, or potential handicaps can be integrated with normal children at an early age and provided with educational experiences which can help them overcome or prevent handicaps.

The twelve programs referred to earlier, which are administered or monitored by the BEH fall into three general categories - namely: research, educational services, and training of personnel. The three divisions are organized along those lines. Dr. Frank Withrow is Director of the Division of Educational Services; Dr. Max Mueller is Director of the Research Division; and Dr. Bruce Balow is Director of the Division of Training Programs. So far, I have discussed mostly the "services-type" programs. You have heard discussions from others here which fall into the area of research for the severely handicapped. In looking over the BEH funded research projects for the multiply handicapped, we find a scarcity of awards, I am sure that the Bureau would welcome some well designed research proposals in this area, so I encourage any of you who have some competency along this line to consult with Dr. Mueller about your ideas. The Division of Training Programs has directed some of its energy toward serving the needs of the crippled health impaired, and multiple handicapped. Within the past two years, two awards have been made for conferences to review the state of the art in this area, and develop competency based programs for training personnel and designing programs for the multiply handicapped. One such conference was held at West Point, New York in 1970, and the other a few weeks ago at Tuscon, Arizona under the sponsorship of Columbia University. These conferences have developed criteria to make the professional field more accountable in developing suitable programs in behalf of the physically handicapped.

In summary, the Bureau of Education for the handicapped operates a variety of programs which serve the needs of handicapped infants and pre-school children. By carefully coordinating these programs with other federal programs serving the non-handicapped, it is possible to further the efforts in behalf of our target population. For those of us particularly interested in the multiply and physically handicapped children, it is possible through innovative approaches and creative planning to better meet the needs of this group. We have available programs for educational services, training of personnel, and research. We can set up early childhood pilot programs and practices which have the potential for replication. The State of New York is using some of its federal funds from the BEH to bring us together today to focus attention upon the needs of these children. In returning to our respective communities, each of us can help improve the local, State, and federal partnership in behalf of the education of handicapped children within both the public and private sectors.

Child Advocacy: During the past two years, I have been devoting a major portion of my time to developing and promoting a concept which we now call "child advocacy". This concept is based on what is considered the rights of the child to be provided the services he needs for his maximum growth and development. We have been trying to promote better mechanisms to facilitate better services for children, particularly handicapped children.

While I am aware that each of you is here today to find some new ideas which will help you improve your daily activities in behalf of the Mary's, Linda's, and Johnny's whom you are now teaching, there is another part of you which is concerned with the fact that many children like your Linda's, Johnny's, and Mary's are not being served. The children you have currently enrolled are the privileged children. There are many seriously handicapped children in all parts of the country who are not receiving any services; there are many whose services are totally inadequate. Thus, many of us find ourselves advocating for increasing and improving services. I feel that professional, as well as lay groups have the obligation to serve as advocates. For example, the Bureau of Education for the Handicapped is serving in an advocacy role when it sets as its national goal, full and equal education opportunity for all handicapped children by 1980, and procedes to do something about trying to implement this objective. I know that there are some participants at this conference from the State of Pennsylvania who are directly confronted with this need in view of the recent Pennsylvania court decision or decree that all handicapped children, no matter how severe, must be provided with appropriate education.

The Bureau of Education for the Handicapped has already taken steps in the area of child advocacy. In cooperation with the National Institute of Mental Health, it has funded six pilot demonstration projects in child advocacy. Although there is no federal legislation establishing a program called "Child Advocacy." The BEH, using its research and demonstration authority and NIMH using its existing authority have pooled some money - $556,000 during this year, and $1 million for this coming year for these projects. It is expected that the Rehabilitation Services Administration will also participate as a cooperating agency next year making it possible for us to expand efforts even further in behalf of the handicapped.

Child advocacy, as we see it, is an effort to facilitate services for children, to improve the delivery of existing services or mobilize efforts to seek new services. In order to do this, it must contain a mechanism for assessing needs of children, the available resources, the extent of utilization of existing services, overlaps and gaps in services, and the extent to which the services as provided are responsive to the needs of the consumers of services. It deals with the basic child service institutions namely: education, health and welfare, mental health, and judicial. It is directed at institutional change where needed. Child advocacy mechanisms can operate at various levels - National, State, regional, community, neighborhood, etc. Where it exists, it should involve a child advocacy board made up of representatives concerned with the needs of the children or the target population.

There are various types of child advocacy programs which we see developing. Among these are the Advisory Model which confronts the institutions serving children; the Ombudsman Model which tries to represent children through the various systems serving their needs; the Coordination Model which tries to improve coordinated efforts at delivering services; the in-house monitoring system which tries to improve the services within a given agency; and the research and training system for child advocacy.

In expanding its efforts in child advocacy this year, the BEH/NIMH RSA efforts will be directed at trying to solicit models which differ from those funded last year. Those already funded called for neighborhood based models directed at services to all children in the community, but teasing out the services needed by children with remedial or developmental problems. This year we are issuing an invitation to State agencies or National organizations which wish to develop mechanisms for advocacy directed at a target population and pilot test these through local affiliates. We feel that child advocacy is a viable mechanism for providing services to more handicapped children, particularly those who have heretofor been excluded from the existing systems. The BEH views this effort as one of its strategies in reaching its 1980 goal for full and equal educational opportunity for all handicapped children.

One of the advantages of BEH programs, such as, Early Childhood, Child Advocacy and others is the opportunity to develop national networks in these areas. The Instruction Materials Centers and its network originally established through the BEH Research programs, the Early Childhood, the Regional Resource Centers, and now the Child Advocacy Centers all have the potential to have major impact in influencing local agencies to improve their services.

In concluding, my remarks as to WHY WE ARE HERE, I can find no better message than some recent comments by Dr. Edwin Martin, Associate Commissioner of the Bureau of Education for the Handicapped. He said, "A new spirit of urgency prevails,early education for the handicapped children. Concern for cost efficiency, for prevention, secondary handicaps, and for early reduction of handicapping conditions prescribe that children not only be identified and started on education as early as possible, but that they receive effective education before reaching a certain age. This urgency leads to a search for the most efficient means of education possible during the limited time period available. The concept of attempting to reach goals for specific and restricted time frames of pre-school child has not been common in special education for older handicapped children.

"Now is the time to take stock of what we have done and where we are in special education and to consider where we are going and where we could go. In the coming decade we must not be afraid to question our methods and techniques, and even our basic assumptions about education. We have an opportunity now for a new outlook in education for handicapped children and for some major breakthrough in education generally. We cannot afford to waste it."

WHY WE ARE HERE - STATE LEVEL

BY: ROBERT ERB
ASSOCIATE IN EDUCATION OF THE HANDICAPPED
BUREAU FOR PHYSICALLY HANDICAPPED CHILDREN

Mr. Chairman, members of the staff of the United Cerebral Palsy Associations of New York, friends, ladies and gentlemen - I welcome this opportunity to be with you today to speak to you on the subject, Why We Are Here -- the State Level. Children are the world's tools to work with. They are our tomorrow. Theirs it is to build the nations and the races into brotherhood. Children are the little people in our house today. They are small, wide-eyes that look into a dad's and question "why." Theirs the hands that reach for the cookies please. Children are the restless feet that shuffle on the schoolroom floor. They are the shouting voices on the playground. Theirs the minds that puzzle over 6% of 94. Children are our charges, ours, the family's and the school's. Children are tomorrow -- tomorrow's mind, tomorrow's hands, tomorrow's heart. Today, this child is mine and yours. What will we do with our tomorrow? Most toddlers quite easily learn those things that are common to childhood. An entirely different prospect, however, faces the infant who can't turn over without assistance,or one with severe birth defects,or one who is deaf, or those who are mentally retarded. Life for them presents formidable obstacles. It can, for example, mean hours, days - and even weeks of painstaking instruction and practice to achieve a semblance of normal activity. The time has long since passed when we may permit ourselves the luxury of giving lip service to the preschool education of the handicapped.

Let me ask you "Who Speaks for Children?" You must and we are here to support you. The illustration of doing nothing was set forth many years ago by Madame Chiang Kai-shek. She tells us the following story: One day we went into the Heng-Yang Mountains where there are traces of a famous pavilion called "Rub the Mirror Pavilion" which was built over two thousand years ago. It will perhaps interest you to hear the story of that pavilion. Two thousand years ago near the spot was an old Buddhist temple. One of the young monks went there and clasped his hands before him in an attitude of prayer and murmured, Amita - Buddha - Amita - Buddha - Amita - Buddha. He murmured and chanted day after day because he hoped he would acquire grace. The Father Prior of that temple took a piece of brick and rubbed it against the stone hour after hour, day after day and week after week. The little acolyte being very young sometimes cast his eyes around to see what the old Father Prior was doing. The old Father Prior just kept on his work of rubbing the brick against the stone. So one day the young acolyte said to him, Father Prior, what are you doing day after day rubbing this brick on the stone? The Father Prior replied, I'm trying to make a mirror out of a brick. The young acolyte said it is **impossible to make a mirror out of a brick.** Yes, said the Father Prior, it is just as impossible for you to acquire grace by doing nothing except, Amita - Buddha all day long, day in and day out. We all know that actions speak louder than words. Longfellow tells us that action is the proper fruit of knowledge. The materials of action are variable but the use we make of them should be constant. In the words of Roussaau, to live is not merely to breathe, it is to act.

The Bureau for Physically Handicapped Children has the responsibility for the administration of programs offered to physically handicapped children in the school districts of New York State. The types of physically handicapped children included in this responsibility are the blind and partially sighted, the deaf, and the hard-of-hearing, the orthopedically handicapped including cerebral palsied children, the neurologically impaired including the brain injured, the language imparied including the aphasiac, the speech handicapped including those children whose speech is in need of correction due to hearing loss and the multiple handicapped. The Bureau is concerned with the initiation, development and expansion of comprehensive programs from the pre-school level to the secondary level for the physically handicapped child.

It is estimated that in 1970 there were 9,600 physically handicapped children receiving instruction in special classes in New York State. By now, this may have increased to 10,500. There has been an increase in pre-school programs for handicapped children. Greater emphasis is being placed on earlier programming for children requiring a head start in socialization, motor training and educational needs. A continuing concern and problem in educational programming is being focused on children with multiple handicaps. In conjunction with this concern the Bureau for Physically Handicapped Children co-sponsored with the United Cerebral Palsy Associations of New York State, an institute entitled, "The Development of Programs for the Early Education of Children with Multiple Handicaps." I am sure that in this group today there are those who were with us last March 7, 8, 9, and 10, in the institute which involved approximately 50 teachers and administrators of the physically handicapped. Many physically handicapped children are benefiting from the several pre-school programs in operation throughout the State. Initiated by the local school district and supported by funds made available under Title VI-A of the Elementary and Secondary Education Act, these programs offer the young handicapped child an opportunity to develop skills in socialization, reading readiness and the areas in which the child might profit prior to his entry into the more formal public school program. The handicapped child population seeking services in the schools is changing. No longer are the schools faced solely with children representing discreet categories with one major handicapping condition. Large numbers of children in need of training and education have two or more disabilities. There is need for more intensive educational diagnosis of handicapped children, so that programs can focus more attention on remediation, particularly during the early years in school.

With the rapid advances being made in the diagnosis, evaluation, and treatment by the medical profession, children who formerly would have died or whose problem was not recognized until they were much older, are being referred for educational services at much earlier ages.

We expect that the number of handicapped children will possibly grow larger in terms of an expanded definition and earlier recognition of handicapping conditions.

We have seen a sizable increase and interest throughout the country that the schools should have the responsibility down to the pre-school level, that is to include nursery school programs as part of the schools total responsibility. The Board of Regents of this State have taken a position calling for this and State funds are presently being used to finance experimental programs for pre-school children. "There is no doubt that all children can benefit from early education. Their thinking and ability to learn are enhanced by exposure to a wide variety of materials, equipment, and activities under the guidance of competent teachers. The steps taken to date in New York State - private nursery schools for those who can afford them and public pre-kindergartens especially for the less advantaged - are only a beginning. The Regents believe that it is advisable to extend educational opportunity with public support to include 3 and 4 year old children in the State educational program. The Regents, therefore, propose that the State adopt a long range plan leading to the establishment of free public education for all 3 and 4 year olds whose parents wish them to attend school. The Regents recommend that State financial support be provided on the basis of "approved" costs - that is, all costs necessary for a quality program for pre-kindergarten children. Financial provision should be made for building construction and the initial equipping of classrooms as well as for general State aid to school districts to operate these programs.

The goal must be quality education for all young children. Inadequately conceived and poorly executed programs will do more harm than good. Programs must be designed to develop all aspects of the child - his physical, social, intellectual, and emotional characteristics; imbalanced stress on any one area (such as the intellectual or cognitive) must be avoided. Since the task of raising young children is essentially the responsibility of parents, close parent collaboration and involvement are absolutely essential.

The Regents believe that the program for each child must foster a sense of trust in adults and in the environment, develop an adequate self-concept with feelings of confidence and personal worth, and provide rich experiences with sights, sounds, manipulative materials, books, and pictures in a variety of settings. Through careful organization of this flow of stimulation, the child must be helped to develop his mind and body, integrating the functions of communicating, reasoning, problem solving, imagining, and self-discipline.

Federal legislation has been passed and funds are now available to subsidize pre-school programs through the Handicapped Children's Early Education Assistance Act, P.L. 91-230.

Our concern during these three days is about a group of children who present a real challenge to all of us in spite of the resources at our disposal. "Why are we here?" Certainly, we want to press for a pattern of service that will break down further those barriers confronting these children so that we might help them reach levels of readiness to enter a school program at age 5, not necessarily the usual structured program we traditionally think of, but rather a program in terms of the unique needs of these children. Certainly, we are here to learn from one another.

A quick glance at the program reveals names of persons who already have a high degree of sophistication and expertise in the field of our deliberations.

Thus we already have a body of knowledge about the problem at hand.

We are here to work with you in long range planning and to develop a greater degree of coordination between the public and private agencies working on our common goals.

In the movie, Ben Hur, you may recall the Jewish steward of the wealthy Hur family and the giant slave he teamed up with. The slave's tongue had been cut out and the steward, tortured by the Romans, could no longer use his legs, yet he remarked courageously, "Together we are a considerable man".

We realize that we shall not accomplish always our dreams and hopes, but let us light a candle rather than curse the darkness.

I believe it significant that Shakespear gave Sir John Falstaff of odd bearing and physical defect - these noble words to say, "I will turn diseases to commodity." That surely is the final word on the subject.

A SERVICE APPROACH TOWARD THE IMPROVEMENT OF PROGRAMS FOR INDIVIDUALS WITH NEURO-MOTOR AND SENSORY HANDICAPS IN ADDITION TO MENTAL RETARDATION

BY: UNA HAYNES
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Advances in medical science are contributing to the survival of severely damaged infants and appear to be increasing the longevity of individuals who have extensive neuromotor and neurosensory disabilities, in addition to significant mental retardation.

The nature of the developmental needs and the personal care problems of such individuals presents a unique challenge for parents, and the professions involved, as well as for the individuals who must cope with these multiple disabilities.

There are both ethical and economic bases to support the application of special approaches to aid these individuals. For some, it could mean the ability to function in the community; for others, an earlier return to the community from a residential institution; for the longer term residents, an improved level of health, greater functional independence and mobility, which could facilitate their participation in a broader range of residential programs.

There is evidence that few community or residential facilities have developed effective programs to respond to the specialized needs of these individuals. Many rehabilitation centers are still oriented primarily to serve those whose disabilities result from illness or trauma originating later in life, (rather than incorporating a developmental approach for those who have never known normalcy.) Additionally, individuals with severe and extensive handicaps, who do not respond readily to the generic programs of these Centers, are soon discharged or relegated to minimal surveillance in a token home program.

While a host of innovative new community approaches are evolving as alternatives to institutional care, this rubric of foster care, group home, advocacy and related service is still denied to the great majority of those who are most substantially handicapped.

If family members of the severely disabled cannot accept the recommendations to "put the child away" in a residential institution, the community usually offers little more than respite care. With few exceptions, such respite for the family provides the individual with little more than a change of place. Custodial rather than habilitative in approach - a few hours a day, in a bed, near the wall, or on a mat in a corner, at the day care center; a bed, amid the aged and the senile in a nursing home constitute the program of care in many of the so-called progressive communities.

Within the institutional milieu, this target population tends to be excluded from the mainstream of service and relegated to minimal life support. Attendants assigned to these residents are frequently paid at a lower wage than those who serve in cottage life. Sadly, sheer economic factors thereby foster the flow of the more able attendants away from the severely handicapped to serve their less disabled peers in the cottage life milieu.

When colorful homelike units are designed for the less handicapped residents in the institution, this severely disabled population remains in a hospital type ward, twenty, forty, and more in one room. Even architectural designs still on the drawing board, as well as those of existing facilities, replicate this type of architectural plan. When small family groups who relate to cottage parents are created for the less disabled, attendants continue to move like workers on an assembly line, or wards for the severely impaired first changing, then bathing, then feeding row on row of residents. Then new equipment is designed to those who go to school, get to workshops, romp in playgrounds; these residents have braces, which lie rusting in the closets, unreplaced; chairs (purchased on bids) that do not fit and none adapted for their use. Deemed bedfast, what use for pretty clothes and shoes. Deemed bedfast, when they come, it's bedfast they remain or at best change an immobile status in the bed for a similarly immobile and function inhibiting in a chair or status in supine on the floor. Life they have, but liberty and the pursuit of happiness are absent.

When the advent of new monies in the 60's permitted some institutions to equip a rehabilitation center on their grounds, the model of programming which obtained in the community was often copied, item by item. Thousands of dollars spent on parrafin baths, and arm range of motion wheels for the arthritic; heavy pulleys and weights used by the paraplegic, special hot pack units for the post polio will be found, but none of these have much relevance to the needs of the developmentally impaired. In a few institutions, there were now budgets for a physical therapist, and occasionally an occupational therapist. Unfortunately, the latter were often seen as arts and craftsmen, rather than the specialists they can be in the fields of perception, activities of daily living, hand eye-coordination, etc.

In the classical model of an interdisciplinary approach to programming, the differential diagnostic study is followed by individualized treatment periods for selected cases. At best, the therapists can thereby select a very few of the residents with most potential, to serve, out of the hundreds, and in some institutions, the thousands, who might benefit from their expertise. In a desperate attempt to share their knowledge and skills, hoardes of aides began to be trained. The handful of professional nurses available in the institutions trained nurse aides, the physical therapists, physical therapy aides, the speech and occupational therapists and others, each trained their own special aides. Coming up to the wards for a few minutes daily, or on a weekly or monthly basis, each aide did her own thing for a few moments, while the harrassed parent surrogates of these residents rushed off to complete household chores, or take a coffee break. Then, with exceedingly few exceptions, these interventions stopped the moment the specialized aides left the floor. There was no motivation, special knowledge nor training sufficient for the generic aides to carry on. They weren't special. They were just the "feed and clean up" crew.

Pre-Planning Period - A look at the status quo

At first, there were three who got together to share concerns and lay the groundwork upon which this project was evolved: - the late Ida Axelrod of the National Association for Retarded Children, Doris Haar of the Division of Developmental Disabilities (then the MR Division of the US Dept. of HEW) and Una Haynes of United Cerebral Palsy Associations. What were the clues we might use to try to help foster a better program of services for those with severe neuromotor and neurosensory disabilities, in addition to significant mental retardation?

Because of the very nature of our work as staff members of national organizations, we three had shared unique opportunities to visit and serve as consultants in a great variety of community and residential programs for the cerebral palsied and the retarded. These opportunities not only made it possible to face squarely the situation which now obtained in these facilities, but also to meet and counsel with colleagues who shared the same concerns. These visits to over 200 facilities in 49 states also revealed some frustrating truths. Return visits to the same institutions disclosed, in many instances, that little change had occurred following the seminars or the consultation visits.

The absence of appropriate services on an around-the-clock basis was continuing to contribute to the individual's physical, emotional and social deterioration, which in effect resulted in little more than gradual enthanasia by attrition. In the multi-purpose institution achieving measurable gains in cottage life, these back wards were like a cancer. In the facilities where only the most severely handicapped have been segregated in some states, concerned members of the staff were sometimes close to utter despair. Yet if they left, who would serve these children and adults for whom many had the most sincere concern?

How can one truly espouse the normative environment, hold high the human rights of one group of residents and condemn others to a living death. How can the wealthiest nation in the world continue to provide increasingly expensive and difficult to staff segregated ghettos with minimal life support for hundreds of its citizens, when the very constitution of this country speaks of their inalienable rights to liberty and the pursuit of happiness, as well as life itself?

Where were the clues to what might be done? Who would help us? Were there any clues to be found in centers which were beginning to gear their approaches to those whose difficulties arise before, at or near the time of birth, affecting the total process of maturation, rather than occurring later in life? - a developmentally oriented habilitation approach rather than the more classical model of rehabilitation? What did some of the neuro-developmental approaches in therapy, the proprioceptive neuro-muscular facilitation and other techniques have to offer, when therapists had these, as well as some of the more classical modalities, at their command?

What happened when pediatricians and pediatric neurologists shared their expertise with orthopedists and other medical specialists? What happened when nurses are able to integrate new knowledge about the way babies seem able to learn, even during the first weeks of life when nurses can be knowledgeable about cognitive, language-verbal aspects of development, as well as the more strictly physical, social-emotional components of nursing interventions?

It is beginning to become abundantly clear that many unwarranted secondary disabilities affecting the severely handicapped could be effectively prevented if babies deviating from the norm were helped during the first days and months of life. Before an aberrent reflex pattern is permitted to adversely effect handling and the succeeding progression of neuromotor development and before the contractures occur, there was evolving a broad armementarium of new knowledge and skills which the up to date staff could bring to bear in an eclectic approach to management. The well prepared nurse was also becoming aware of and able to help foster whatever potential the infant may have left to him for cognitive and language verbal development, as well as meet the more strictly physical-emotional needs of the handicapped infant. Just as there is no excuse for the separation of the so-called medical, versus educational models of service in an institution later in life, such segregation should no longer be tolerated during the potentially most rapid periods of learning which occur during infancy. If this was to take place, however, new models of service must evolve. No one should be deprived of the special knowledge and strengths within all the professional disciplines which can be brought to bear upon diagnosis and evaluation in the interdisciplinary model of service. The nurse needs every kind of help from her therapy colleagues to incorporate this type of handling. Other disciplines also needed these and other types of sharing in new ways. Most importantly, the parents and parent surrogates needed to functionally integrate habilitation goals on a social, emotional, language, verbal, as well as physical point of view.

The classical interdisciplinary model directs that while the team will talk over and decide together what the program shall be, each discipline then proceeds to do its own thing on behalf of the child. The physical therapist, working primarily on areas of body mechanics and locomotion; the occupational therapist on problems of perception; hand-eye coordination and activities of daily living; the speech therapist, the total rubric of language verbal development; the teacher, a child's cognitive development; the nurse, the promotion of health and prevention of disease. Carried to all parameters within this model, still further differentiation of service to "pieces" of the child and family can occur (with the role of the psychologist, social worker, recreation specialist and others, each directly involved in one facet of the program or another.)
In studying cases with high potential, we found children relating to as many as seven and eight professionals a day or each week - the family faced with home program orders which actually added up to 18 hours a day!

With infants, it soon became abundantly clear that they simply cannot tolerate too much handling. Even two or three professionals can constitute an overwhelming variety of authoritarian adults. This has led to the evolution of new models of service. It is granted that each specialist is the one who should, on the basis of generic knowledge and skill, test out the most appropriate modalities to be used at a certain age and stage of development. Thereafter, in order to cut down on numbers of people handling the baby, a primary programmer could then be taught the therapeutic handling of the infant. She could help functionally integrate therapeutic goals throughout the daily life experience of the child. If pre or post surgical states, a rapid growth change or other factors demand a specialized "treatment" from time to time on a one to one basis by specialists, could one member of the professional team be taught by her colleagues how to help this parent carry through for a few weeks and incorporate the total program without deleterious effect on the family life style? Could one team member become the primary supporter without all other team members being directly involved at all times? This would mean role release! One team member would need to teach the other precisely how to follow through and do so to the limit of licensure. Each would need sensitivity sufficient to detect when the situation warrented direct re-evaluation or direct intervention by the other members of the team, if this occurred between scheduled re-evaluation dates. There would be no release of responsibility or accountability. The selection of the team member to serve as the principal support for the family could change as the child or the parent needs changed or if it was found that one member, the parent and child seemed to relate particularly well to each other and should continue in this special relationship.

Differentiating this from the more classical concept of the interdisciplinary model of service where each professional continues direct intervention to do his own thing - this new concept began to be designated as the cross-disciplinary approach. Since more than one modality, be it Bobath, Rood, Piaget, Skinnarian or other, was involved - the term cross-modality, cross-disciplinary approach was coined to draw attention to all the elements involved.

Other considerations came to light. Rather than training more PT aides, OT aides, nurse aides, teacher aides, to work outside the generic therapy room or classroom settings, the parents or parent surrogates might be taught to put it all together on behalf of the handicapped individual in the course of multiple daily contacts and interaction. On the ward, instead of an isolated ten to twenty minute contact by another aide, the primary parent surrogate aide could follow through. This would not mean that the individual would be restricted to one place or to one person, but it would reduce the bewildering complexity of trying to relate to a horde of personnel. Trips off the units could be for fun or to go to class, but not to send "feet" to one place and "arms" to another on a piecemeal basis all the time.

Specific Planning - Clues Worthy of Attention

Since our target population had such extensive physical disabilities and many were still functioning on the infant level, what could be done to marry the so-called educational model to the medical model in the institutional milieu? Maybe we would need first to have mini-teams of therapists and nurses using a cross modality-cross disciplinary approach to raise the level of function sufficiently to mobilize the attention of other professional colleagues on their behalf.

What have we seen?

One nurse learned to work closely with therapy colleagues in a variety of ways. She had no therapists in site, but a consultant therapist taught her how to evaluate, measure, construct and fit inserts for wheel chairs. This was just one measure in a broadly based program of personal social, as well as physical rehabilitation. But previously bedfast or floor fast residents began to see the world around them, hear what was going on, use hands more functionally, get out of doors, even go downtown. Cottage life personnel began to take an interest and help out.

Similar changes were seen elsewhere. Could these measures be taught to new teams? Could they, in turn, help the parent surrogates?

We found a friend and strong ally in Harvey Stevens, who was then superintendent at Central Wisconsin Colony, and many able members of his staff. Here, there were some studies made on the extendor role of nursing and therapy. Here, there was instituted a role exchange study with nurses going to work in the therapy departments and therapists assigned to the wards, to more fully live the professional life of the other; to develop new knowledge, enhance the basic respect one accorded the other. No longer a secret exclusively known to therapists, how to reduce extensor tone! They learned in this and in many other ways to work together and do so where the residents live - not just in a therapy room.

Here, too, there were definitive trials of the fantastically complicated job of re-scheduling attendants serving the most severely handicapped, so that each aide - mother or father had his own "family group", rather than serving all residents in the unit. With shifts to contend with, weekends and holidays, each little family had to have three to five or six parents in the course of a week or month. However, the individual no longer had to contend with fleeting contacts by "floating" staff, or ten to twenty "parents" in the manner which still obtains in so many institutions, and the children benefited.

NASSAU PRE-SCHOOL PROGRAM

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We are all aware that the extent to which a cerebral palsied child succeeds in life situations today depends to a large degree upon the facilities which are available for understanding and guiding them, especially during the early years.

In our discussion this morning, I should like to acquaint you with the programs we have made available to the multi-handicapped child at United Cerebral Palsy Treatment and Rehabilitation Center in Nassau County.

There are presently fourteen classes within Developmental Programs at our Center. Two were designed primarily for those children in the 3 - 4 year old category. We call these classes Early Developmental Training Programs. These are diagnostic groups of youngsters, who may or may not be academically oriented. Two of our classes were designed primarily for children in the 4 - 5 year old category who we know are academically oriented. We call these our Pre-school groups. A basic philosophy is that these children need not accept failure as a way of life. We know that the roots of social adjustment take place at this time and that these are very critical learning years. We are providing 6 programs designed primarily for the child who is over 5 years of age, who because of physical or mental handicaps find that there are no programs available to them at this time. We call these Intermediate Developmental Training Programs. We are providing an organized and orderly program of stimulation and experiences; of course, our expectations are different for this group of youngsters. There is one program designed for children who are over 13 years of age. This is an all day Program which is really good day care in an educational setting. Three of our Programs called Avocational are designed primarily for the young adult, over 21 years of age, and it is a diversified Semi-Recreational Program for the young adult whose needs cannot be met in a sheltered workshop setting.

We will be primarily concerned today with our Pre-School Programs. The following is a slide presentation.

Pre-school is an experience -
It can be wonder -
for some it can be challenge -
And certainly it can be accomplishment -
It is a time to be -
And to feel - And to know:
A time for small attempts and step by step achievements -
Pre-School can be painstaking work to make an ashtray -
Build a snowman -
bake a cake -

It's having a name - a selfhood -
It's finding out that you are not alone in the world
 but that friends are there -
It's reading a book for the very first time -
It's tasting -- and it's listening -
This is childhood - the chance to be little and the right
 to grow -
This is our Pre-school program - designed to bring the real
 world to the child who may be physically unable to
 search it out for himself.
We believe that childhood is a very special time -
It's assurance that the sun will shine - that today is full
 of promise -
that tomorrow can be better -- that the child is someone special.
Here at the United Cerebral Palsy Treatment and Rehabilitation
Center - -
A child is very special - - - Our world was created for him - - -

This is Michael - When he was 3½ years old - he was ready for a pre-school program - like many 3½ year olds - but unlike most 3½ year olds - Michael's parents knew that his needs would be different -- you see, Michael has cerebral palsy - Generalized Athetosis - with mixed spastic quadriplegia.

They soon learned that Michael was going to need a highly specialized pre-school program - the first step toward a realistic educational goal. They learned, for example, that he was going to need special teaching methods, adapted classroom materials and different kinds of learning experiences.

How multi-handicapped children learn, what ideas they get about people and the world - as well as how they feel about themselves, may all be based on their pre-school experience. Some handicapped children like Michael - have the same potentiality - certainly the same curiosity - and the same basic human problems to face in life - except that life has given them some extra problems which no child should have. Their opportunity to explore the physical world have been limited with a consequent lack of opportunity to develop physical controls, skills and coordination, or to know themselves as persons who have these skills.

Most have had limited experiences in problem solving - in the satisfactions that come from being able to accomplish a simple task.

These are Michael's friends at school. The members of our staff knew that the configuration of personal assets and liabilities make each cerebral palsied learner in this room quite distinct from any other - - and so in planning curriculum objectives for each child, the following was considered - that a child with cerebral palsy is a handicapped learner because he is usually far from the developmental level of other children his age - that the poor quality of language in 50 to 75% of the children will also seriously handicap their attempts to learn. - that most cerebral palsied children are handicapped as learners because their range of experience has been so limited.

The program designed for these special children was comparable to what one might find in any good pre-school setting - with some modifications and adaptions imposed by the childrens' disabilities. Our staff made sure that the following normal developmental categories were included - - self awareness - sensory motor perceptual development - language, communication and cognition - and social development.

Our approach to education and habilitation is an interdisciplinary one - which of course means that we must function as a well coordinated team. Our interdisciplinary team - members include a medical staff - psychiatrist - psychologists - physical therapists - occupational therapists - speech therapists - social workers - and teachers - all who have the difficult task of organizing, developing and evaluating learning experiences that will have both value and vitality for children like Michael.

How did Michael come to be part of this special program? When he was two years old, he was referred to our Center by his pediatrician. His mother's first person to person contact was with a social worker. In their initial interview - medical and social information about Michael was obtained - then they proceeded to evaluate the feasibility of utilizing our facilities and the kinds of treatment available.

A battery of medical examinations followed - including Pediatric, Orthopedic and Neurological consultations. A program was outlined for Michael and his family; in this case Michael was provided with a management program which included physical therapy and speech therapy. Michael's growth and development were monitored periodically by the medical staff and an assessment of changes was maintained.

When Michael was almost 3½ years old, he was screened for admission into the pre-school program. This included a battery of psychometric and physical measures. At this time, his parents received an orientation to the program and Michael was given the opportunity to spend a day in school and to meet his teacher and teacher aides. Like most mothers of new pre-schoolers - Michael's mother had real concerns - she knew that Michael had had a minimum of independence training and had demonstrated in therapy - an unwillingness to even try - a kind of indifference. What possible kind of program could a child like Michael participate in? How will he make his needs known? How will he communicate? Will he be able to follow directions - after all - he could not walk and he could not talk. She was surprised to learn that as part of the basic philosophy at U.C.P., the program was structured to be as much like a conventional pre-school program as the children's disabilities permitted.

By this time - Michael's medical record had been carefully reviewed by his teacher and individual meetings with those therapists who knew Michael were arranged.

Michael was introduced to his new experience in September. Hi Michael - his first day on the bus - that's his bus driver. He brought an "Apple-for-the-teacher" tag which he received in the mail from his teacher a few days prior to school - and so of course, his driver knew just where to take him.

One of our first major concerns was that Michael had to be properly seated. He was evaluated by a member of the Physical Therapy Department, and recommendations were then made for a special chair which would better enable him to take part in his classroom activities. His seating is continually monitored to be sure that he is able to make maximum utilizations of his learning experiences.

Each child's chair may be somewhat different. Beth has a modified chair which has been designed especially for her. Let's take that first step with Michael now - through the experiences in living which have been provided to him in our pre-school program.

One peek into our room and we see a free play time - usually the first daily activity. Michael was lucky - for in school he was introduced to a rich manipulative environment - where he found many opportunities for social experiences and creative play.

I always feel a little uneasy about that "free play" label - since it implies a kind of "anything goes" free for all atmosphere, and certainly that is now intended. The free part means that the children are free to select the activity in which they wish to engage - free to use them in their own individual ways. They are not free to misuse them of course, or to use them in ways that are disturbing to others.

Play to the pre-school child is a very important part of the day. As a matter of fact, we "play" all day - for play is our work in pre-school. But to the deprived child - - and the handicapped child is a deprived child, he is in a very real sense - "out of work."

The children in Michael's class will be given many opportunities to dramatize and reproduce the meaning of their experiences through play - because it is one of the most important ways in which children gain knowledge about themselves and their world.

Our room is organized to issue invitations to a variety of activities - blocks are always on the shelf - the doll corner is set up - table toys and manipulative toys are accessible. Dough or clay may be set up with suitable utensils. Many of our activities are those designed by Mdm. Montessori - valuable to us because of their accent on training the senses.

Parts of the Kelp Program are used. From this program - perceptual skills that are essential to reading are taught as block designs, bead patterns, safety signs and other activities that have immediate appeal and attractiveness for the 4 to 5 year old.

During this activity, children are encouraged to choose the materials that appeal to them. Some of Michael's friends like Janna - will leap into the room - sure of what they want to do; others may need to wander and watch a little before becoming involved.

During this work period, there will be a busy hum of activity - some building with blocks - some playing at the sand table. To the casual viewer - it may seem like bedlam sometimes - but to the trained eyes and ears of the teacher, it represents a scene of multiply learning situations in which children are engaged in working out the challenges involved in each play situation.

In the block area, for example - these questions are being asked - How do you balance a big block on a small one? How do you bridge an open space?

Michael finds blockbuilding more satisfying at the table. He cannot successfully manipulate the large ones, so he is encouraged to try to find the same answers using the smaller ones. The teacher or aide - aware of all the challenges - is on hand - to help the builders find solutions.

Beth's favorite toy is a Montessori designed activity called cylinder blocks. Each cylinder has a round knob for easy grasping - they come in a set of 4 - each at varying sizes and dimensions. The exercise is a simple one - it consists of taking out the cylinders - mixing them up - and putting them back in the right place. Eventually, we hope that Beth will do this with a blindfold.

The materials serve to educate the eye and to distinguish differences in dimension. But let's see, what is really happening to Beth as she plays with this toy. She is training herself to observe - to make comparisons between objects - to form judgements - to reason and to decide - and it is in the indefinite repetition of this exercise of attention and intelligence that real development follows. It is an excellent readiness activity for holding crayons and pencils, and for developing muscular coordination of her hands and arms. Besides IT'S FUN TOO! Beth is an athetoid - who has involuntary movements of her arms and hands. Notice the position of Beth's hands. Beth has been learning in Occupational Therapy that when she is engaged in activities,she should keep her right hand down at her side, even under the table, in order to avoid an abnormal pattern of movement - or she will not be able to achieve the best function. She only has to be reminded once in awhile now. Come on Beth, put your hand down - that a girl!

This, of course, points out that the pre-school's relationships with the Center's occupational, physical and speech therapists is functional; that is, we reinforce the therapists "teaching" by incorporating the goals into play situations.

Our children are also given the opportunity to use materials from which they may derive satisfaction, enjoyment and of course, feelings of mastery. This could include work with pebbles, shells, stones and seeds. They are offered many sensory experiences with water, clay and finger paints - and yes - peeling oranges - - they are offered creative art activities with a variety of art media - an opportunity - through dramatic play in a housekeeping corner.

Even our most severely handicapped child can enjoy the rhythm and movements of fingerpainting and play dough - and although many will be entirely reliant upon being guided to do this - it is a means of introducing a new enjoyable sensation to those who are severely handicapped.

The conventional educational materials sometimes have to be modified. To compensate for the incoordination and restricted hand movements of some of our children, we use puzzles with knobs on individual pieces - we tape drawing paper to the table surfaces and use very large crayons.

We use different tasks for those children who have difficulties in perception and organization and to hyperactive behavior. These include the use of form puzzle boards with inserts of basic shapes and configurations. Shape discrimination problems are introduced in as many different ways as possible.

While the children are playing, let's go back a bit and turn our attention from Michael to Michael's parents. How did we get them involved in our Program? Quite early in the school year a Developmental Parents Evening was arranged. The Supervisor of our Social Service Department was one of the speakers. It is most important that parents understand our Educational and therapy programs - for much of what is important and appropriate to the child in the school setting is applicable to the home. Our purpose - to develop a total life program for the child.

We introduce our parents to the educational toys and equipment and Michael's parents learned - - that toys are important tools for learning. At the same time, parents are given the opportunity to make contacts with other parents of handicapped children and to share some common problems.

Michael's mother and father will even get to sing some of the songs which Michael will be hearing, via our expert Music Director.

During the conference hours, parents may be told which games the children play well. Suggestions are also made as to the best kind of instructional and creative toys and materials parents may purchase.

They are shown how our children are motivated to learn - via films, slides, books, filmstrips, art and music in various forms.

At another Parents Meeting - - parents were treated to a Fashion Show. The children were the models, and the clothes were designed by our own Occupational Therapy therapists. Parents have many problems concerning comfortable clothes for a handicapped child - and many very helpful suggestions were made - not only in purchasing new clothes but in adapting clothes.

See how much easier it is for this young lady to wear a poncho, rather than a coat - and one big problem was solved for many - How to fit snowpants over leg braces.

Parent Discussion Groups - - offer another dimension to parent participation. There is Michael's mother in her discussion group a few weeks ago. Sometimes teachers or other staff members are invited to join the group. Through these discussion groups, parents exchange ideas and attitudes and help one another in problem solving. The social worker's role is to provide a framework within which parents interact, and to act as a resource person. We know that many find much more help through group experiences than in individual interviews. We are all sensitive to the needs of parents of young handicapped children - as well as to the needs of the children.

Back into our room for the next activity. Snowman role call - it's a favorite one, and through this activity, we are encouraging Michael and his friends to learn about themselves. Many of our efforts are aimed at aiding each child in the exploration of his personality and abilities. Such self-examination is a prerequisite to the development of the concept "me" and essential to the formulation of a solution to that all important question, Who Am I? It's only after this step has been taken, can he begin to perceive himself as an unique individual with special qualities, talents and capabilities. The purpose of this activity then is the development of self awareness, and the enhancement of reading and arithmetic skills. Enabling a child to recognize the sound and sight of his name are important first steps toward discovering just who he is. In fulfilling its self awareness goal, the activity also reinforces proper sex identification. The snowmen were originally teddy bears and color cued.

After awhile Michael did not need the cues any more - - now, of course, we are quite sophisticated, we've grouped them by sets - - we rote count - - we're developing number concepts, and we are introducing phonics. All in the same activity. There are endless possibilities, and what seems like a relatively simple activity often involves much planning and has many intrinsic motives.

Gross Motor. Our Gross Motor Program, which also involves Sensory-Motor training as well, is provided for all pre-schoolers and consists of a wide range of physical, perceptual, pre-language and language activities - - depending upon the abilities of the children.

In the following slides you will see a speech therapist, occupational therapist and physical therapist working as a team in the classroom to provide the stimulation most beneficial to the children they are working with. Each therapist looks at his activity from a different point of view and emphasizes somewhat different aspects, but their goals are the same - to provide the child with activities which will benefit him in his daily experiences. In being aware of the sensory-motor aspects of development, the child must learn to know about his internal self at the same time that he is developing that concept of "me" - not the scientific aspects of his body, but the internal awareness of how he moves and fits into his environment. Children, like Michael, at the beginning of the year are evaluated to determine their abilities and disabilities and are grouped accordingly. While Michael and his friends are being guided by therapists, they put themselves through gross motor activities which increase their motor skills.

In addition, they are stimulated to learn new language concepts, they are encouraged to be more aware of their bodies and where they are in relation to their own environment, and to plan how to perform the movements asked of them. Competition provides increased stimulation and motivation for these children.

Ball playing - - is a favorite method of creating a real match between the eye and hand for a child. This matching must take place to sophisticate the eye control so it then leads the activity of the hand. We start with real large balls - the child must feel and see at the same time. Catching and throwing can become a new game with a different size ball. Sometimes the task is to throw it at an object - - knock it down, throw it through an opening, hit the ball with a stick and so on. There is no limit to the variety of tasks that can be performed with a little ingenuity. It is not the task in its directions that is so important, but the matching and integration of the various senses that takes place - Let it go John! Hurah!

Story time is introduced in a special way, via the happy candle, and then it is blown out by the children at the end of story time. We found this to be a dramatic and effective technique for introducing this activity. Literature brings to children the inheritance of the ages and an interpretation of the world in which they live. Michael's teacher knows that such experiences as looking at picture books, listening to stories, having books read to him, enjoying nursery rhymes and finger plays will stimulate his interest in literature and books. (slide of Keith and teacher). The Helper Chart Activity - - is a daily routine where the children choose their responsibilities for the day. This too, reinforces visual recognition of their names. At the same time also, the activity fosters the development and enhancement of social responsibilities and social skills. The mastery of such tasks as carrying, pouring, cleaning, watering plants, sweeping, etc. enhances the child's image of himself.

Often handicapped children are deprived of those experiences by overprotective but well meaning relatives and friends. Many of the activities Michael's brother performs daily with ease, and takes for granted, seem like great feats to Michael - - Daily performance of these duties provides him with small, but significant success experiences, which again enables him to see himself in a more favorable light encouraging him to master more complex tasks.

Here is Mr. Frosty - Michael's job early this week. The task was to choose new color accessories for Mr. Frosty.

Snack time - a most important part of our day. This activity, of course, provides Michael with opportunities in social living - and for the practice of the skills being developed in his work in occupational therapy. During snack time, the children participate in group conversations - they acquire some of the social amenities and develop acceptance of foods. It is also a time for a number readiness activity where the children are given many opportunities for experiences in one to-one relationships and rote counting.

A daily routine - let's check on the therapy schedule for the day. This too became a learning situation. Sometimes a youngster is fearful about being taken from the group - this is especially so at the beginning of the year and the chart helped many to understand a time sequence and it eventually helped to encourage some children who were fearful to be less so - and now when this lovely lady in blue arrives (she's a volunteer) Michael is quite eager to go.

During the week Michael is scheduled for speech therapy. Here he is in his first step toward learning how to use a straw; this being a joint project with both his speech therapist and his occupational therapist. We found that cup drinking was not a feasible method of liquid intake for Michael, because of a lack of lip and tongue coordination. It was decided that developmentally Michael was ready to learn to drink from a straw - which certainly will provide a more satisfying and rewarding vegetative function.

Our speech therapist knows that communication for the child with motor handicaps cannot be overstressed. These children need opportunities to talk - to be listened - and to listen. Many children with cerebral palsy are likely to receive minimum satisfaction from verbal communication - as compared with other children. Michael's teacher and aide have become sensitive to that other language - the language of gestures, gross body movements or eye motion - the only way some of our youngsters can express their needs and desires.

Michael's particular therapy schedule will also include a program in physical therapy - he is also scheduled for occupational therapy - and dressing skills are being developed by Michael with the aid of an occupational therapist.

Wednesday is in-service day at our Center and that is our psychiatrist,Director of our Psycho-Social Unit giving a 6 week course in child development and maturation. Our personnel training is an important center program and currently there are two in-service programs - one for Developmental personnel with the Center staff members as instructors - the other, addressed to the entire staff and presenting audio-visual materials, as well as outside speakers. Our Center has on staff individuals with particular competence in the medical, psychological, educational and social problems of the multiply handicapped, and these staff members are called on as instructors.

In a Center such as ours, where interdisciplinary activity is built into the total program - sharing and exchanging knowledge and practical techniques, provides an indispensible educational process for professionals and para professionals alike.

In Developmental In-service - teachers and aides are made aware that one of the aims of the training goals for each child is to improve coordination to the highest possible level of performance. You know - it only takes a matter of seconds to state the aim of training, but between the capital letter and the period in my last sentence - there are years of daily sessions of therapy with therapists, teachers, parents and child working together toward improved function.

Let's hurry back to class for P. Mooney Time - a language development program. The Peabody Language Program is a very exciting program we use to develop listening, speaking and communication skills through the use of color chips, puppets, pictures and records.

Michael's turn to be Mr. P. Mooney. Throughout the year - we provide parents whenever possible opportunities to share in their child's experiences. Michael's birthday. Halloween - as you can see our parents really do participate. Xmas - take special note at that Santa Claus - we'll meet him again later on.

During the school year, Michael will be seen periodically by our medical staff - he will be evaluated educationally - he will be tested by our psychologist to determine his present level of functioning and the probable rate of development, and routinely examined by an optometrist. All pre-schoolers are evaluated and visual training programs are made available when indicated.

During the week, some of our team teachers will take part in our program. A favorite is our music program. Music is everywhere for children and it is found everywhere in our pre-school program. There is a special time for music - but of course - it is used whenever there is a need. The varieties of activities that are possible with music make this medium ideal for supplementing and reinforcing much of the desired learning for all children.

Participation in a rhythm band - even with bells attached to the wrists is exciting - look at Michael - he is moving - he is participating - He is a person in his own judgement.

Trips

Due to physical limitations, we find that most children in pre-school have had minimal cultural experiences. They know very little of the world around them. Field trips are scheduled a number of times throughout the school year in order to expose our youngsters to those things that will enlarge their concept of the world of shapes - sounds - size and testures and colors. That's Sam, a very favorite bus driver - - Remember our Santa Claus a couple of pictures ago? - that's him and there we are ready for our next experience.

Michael is about to go home - notice the Newsletter pinned to him. This is another way for parents to be given the opportunity to share in their child's experience. Through these Newsletters (weekly) we try to help them understand the kinds of learning experiences all children need to grow socially, emotionally and intellectually and what this means particularly in relation to their child's disability. Many of our non-verbal children cannot answer that persistent question - what did you do in school today? These Newsletters help. Parents also are encouraged to send us their news via letters, so that we can share our show and tell with our non-verbal children at school.

Michael's letter will tell about a visit from our Dental Hygienist - the teacher aide in the picture happens to be a talented puppeteer - who designed and made many of the puppets used to introduce the doctor and the nurse in our discussions. The use of puppets has been a highly effective tool in stimulating the development of language skills.

Michael and some of his classmates are about to take their second steps. Our interdisciplinary team will meet again - a summary of Michael's progress in our program and our recommendations for further schooling will be sent to the school to which he is referred.

In evaluating our pre-school program, we are able to make the following statements:

1. Growth has been greater in some children than in others (but of course, some have come to us much less disabled than others.)

2. In most cases we have observed an increased span of attention and interest in play.

3. We've noted their deeper involvement in materials and broader areas of activity.

4. The widening of their horizons, through the opportunities offered for many new social relationships both with adults as well as with children, certainly served to increase their adaptability.

5. A feeling of increased worthiness and greater independence in initiative and action and an aroused curiosity.

6. They all display a special kind of enthusiasm and an eagerness to attend school - in some children we've observed a decrease in withdrawn behavior, and particularly in Michael's case a lessening in anxiety and an increase in spontaneity.

Our program is a highly motivating one, and ours must be more so than most, for our Michaels have been handicapped from birth. Their limitations are normal to them: they often do not see the need for, nor are they interested in, making an effort to do the things that are hard for them. As you can see, we disguise hard work as "play", we must foster sustained interest and effort, in a word the secret of accomplishment with them is motivation for effort, first and last.

FINANCING OF PROGRAMS

BY: SHERWOOD A. MESSNER
DIRECTOR,
PROFESSIONAL SERVICES PROGRAM DEPARTMENT
UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

As most of you know, Early Care is one of the two top program priorities of the IHF Plan. You also know that a great deal of time and money is being spent by National UCPA on implementation of this priority. This Conference represents one of the relatively few attempts by State or local affiliates to put into practice the mandate of the IHF Plan in this regard. The other top priority of course was on programs for teen-agers and adults. This perhaps will be the subject of another conference.

Some affiliates have raised the question of how they can get into these new areas of services while still carrying on their traditional program. Clearly, the intent of the IHF was that some of the current programs should be shifted to other agencies, or that other sources of funding should be found for them, thereby releasing UCP dollars for the new services. In New York State, you have had the opportunity for a couple of years under 4407 legislation to shift the financing of much of your program for school age children to these State funds. This then should make available some money for the new program areas.

We are not suggesting that the in-between school age children should be forgotten; but we should look at how we are serving them and whether this can be done in other ways. One possible role for UCP is that of advocacy. As children are moved into public school, the affiliate staff should continue to monitor the services they receive and to serve as consultants to the schools and the families. Also, UCPA can help make available consultants of various kinds; e.g., nutritionists from the health department, VNA or from some religious orders. Specialists in adult education to help staff of other agencies do their job more adequately.

The first consideration in dealing with financing of early education program is "What will it cost and where will we get the money?" There is very little hard data on the cost of such programs. Material we have from the five collaborating infant centers shows an average of $3,000 per child per year. However, the content of the programs vary greatly. In one case, it involves a comprehensive evaluation or re-evaluation every six months, plus periodic visits by a nurse or social worker. In another center, there is 24 hour residential care for periods of six to eight weeks. Some data we got recently from Buffalo showed a cost of $2,400 per child per year in their pre-school program.

On this basis, I figure that if you plan to start a program of early education for ten kids, you have to find $2,000 to $3,000 per child per year or $20,000 to $30,000 total. And where do you find it?

Obviously, you must take a careful look as to how this relates to your total budget; and your Board is going to be concerned as to where the new money is coming from. You may find that you can re-adjust your present program to some extent by either shifting segments to other agencies, or by taking full advantage of other funding resources.

You must face the fact that in New York State at least, you probably have to start with your own dollars. You have to have one or two years of operational experience before you can look for funding from other sources.

In some communities, United Fund might come up with some new money provided you can convince them this is serving a vital need. But more likely not. Those affiliates doing independent campaigning appear to be in a somewhat better position. Across the country, UCPA independent campaigns have been going ahead at a surprising rate; something like 19% increase last year and even more this year. Some of this reflects a renewed interest in and response to telethons; but there are other factors involved as well.

Where are the other kinds of resources: Some of this was covered previously by Dr. Withrow and Mrs. Goodman, but I will try to recap.

AT THE FEDERAL LEVEL:

What used to be called the Elementary and Secondary Education Act has been recodified into the Aid to Education Act, and what we used to know as Titles I, III, VI and 89-313 Amendment, has been reshuffled.

Title I now provides for the major grants to state education agencies for all kinds of educational programs.

What was 89-313 is amended for 1973 and carries about 67 million dollars earmarked for children in state institutions. However, this is flexible. This Conference for example is funded from 89-313 monies. Apparently, the thrust is to try to prevent children from getting into state institutions; or to help them get out into community programs. You must work with your local school districts on this, but it is a good idea to talk also with people at the state level.

Title III is for innovative programs in Education and at least 15% must be used for services to handicapped children. This could be more than 15%. You people are certainly creative enough to think up innovative programs. What Mrs. Goodman was talking about yesterday - Child Advocacy, would be innovative. The Cross-Modality approach that Mrs. Haynes discussed is another example; but the inclusion of therapies might constitute a problem here.

Title VI, Section B is for the education of handicapped children. These funds also come through the state agencies. Funding for 1973 is expected to be 37.5 million so there should be a lot of new monies available.

Section C is for Early Education and is handled from the Washington Office. This is the source of support for the three year grant to UCP of New York City and also for our National Baby Project. Several other UCP's have qualified. They have 7.5 million for the current fiscal year and 12 million for next year.

One special section deals with services for blind and deaf children and there will be 10 million in this pot for next year. Some of you should be able to design programs for deaf or blind cerebral palsied children.

Another part provides for the Regional Resource Centers. Your State Association has information on this.

Bureau for the Education of Handicapped is also involved in spending some 3 million of Head Start funds for which the guidelines are now being written.

There are some Day Care monies available from the Office of Child Development, but here you must compete with children of all ages and with the non-handicapped. If you can relate it to a community action agency, this has potential.

If you can operate in a Model City area, you might get funds through that source. They are the only agency that can use Federal funds to match other Federal funds. In any event, you must get a sign off from them if you apply for any kind of Federal money to be used in a model city area.

Title IXA of Social Security is a complex but most important resource. These funds are for "Social Services" to welfare clients or those who are potential welfare clients. In a few states, it has been arbitrarily decided that all families with mentally retarded children are potential welfare clients. These funds are administered through the State Welfare Department with 75% of the money coming from Federal funds. (See a special bulletin on this subject issued by UCPA's Washington Office).

Don't forget CHAMPUS. All military installations have an office of this agency which will pay for day care, diapers, therapy, education and even residential care for disabled dependents of military or retired military personnel.

In our group which was 0 - 18 months, we developed a model which had eight major items, and I will list them first.

1. Rationale
2. Target Population and Sources
3. Organizational Preparation and Policy Review
4. Program Objectives
5. Program Design
6. Program Content
7. Evaluation and Accountability
8. Dissemination and Replication

0 - 18 MONTHS

1. Rationale

a) Parents and grandparents recognize differences and are concerned
b) Research proves something can be done - Intervention can make a difference
c) There has been a change of attitude on the part of Physicians
d) Case finding has been improved
e) A redefinition of function on the part of UCP affiliates has come about
f) We have a conviction that we can make a difference for the child and family

2. Target Population

a) Infants under 18 months who have symptoms of developmental delay or abberation, or as an alternative clinical confirmation of developmental delay.

b) Infants listed on the high risk registry if one exists, or cooperation in an interagency process of referral.

Sources

a) Referral should be accepted from a variety of sources
   1) M.D.'s
   2) Hospital Clinics
   3) Public Health Nurses
   4) Other Agencies
   5) Family Referrals
   6) Child Advocates

3. Organizational Preparation & Policy Review

a) Determination of geographical area to be served
b) Community review of existing services if any
c) Establishment of a professional services committee
d) A review of the organizational charter and By-laws
e) A review and revision, where necessary, of policies and procedures with appropriate governmental agencies

4. Program Objectives

a) To enhance the infant's attainment of his optimal potential for cognitive social, emotional, language, and physical development.

b) To improve the ability of the family to manage and handle the child thru his continuing stages of development.

c) To enhance the family's ability to help the child attain his potential as outlined above with detrimate to the family life style.

d) To enhance professional knowledge and skills of the staff working with the program.

e) To diseminate to the lay public and scientific community the rationale techniques and results of this program.

5. Program Design

a) Evaluation of the infant

1. Obtain past records
2. Work-up the infant and family thru -
   a. Case history
   b. Pediatric medical with attention to any immediate need of infants and family
   c. Complete evaluation to follow which would include:
      1. The family's evaluation of the child
      2. Other medicals as indicated
      3. P.T., O.T., S.T., Early Education, Nursing evaluations
      4. Psychological
      5. Evaluation of family life style
   d. Team Conference -- which provides the bridge between evaluation and design of the program. The group felt strongly this should occur within a stated time limit, preferably of two weeks or at the most, one month.

2. Intervention strategies ----- alternatives

   a. Home based
      1. Degignation of a team member as the primary programmer whose responsibilities would include involving other professional staff and consultants as needed.

      2. A family advocate to follow along and support the family as needed.

   b. Center based
      1. Although we recognized this could either on an individual or group basis and with, or without, family members in attendance, preferance was indicated for a process involving simultaneous interaction of the team with the infant and family members.

      2. This could include observation by other team members.

      3. Transportation arrangements must include child and family member

      4. Consideration to timing of program - evenings, etc.

   c. Combinations of 1 and 2

d. Elements common to both programs were:
  1. Family education and participation either on an individual or group basis.

  2. Designation of a program coordination for each child.

  3. Other elements recognized but not discussed included: staffing, kinds of facilities, frequency of attendance, financing.

6. Program Content

a) The strategies and techniques in working with the child would include many specifics ranging across the entire ruberic of physical cognitive, emotional, social, and language development. Although an effort was made to list some examples under each of these headings, it became clear they are totally inter-related in the Infant's curriculum.

Some examples were as follows:
  1. Improved nutrition assessment of nutritional status and needs by means of a dietary diary and a study of the family's dietary style.

  2. Enhancement neuromotor and neurosensory function:
    a. Procedures calculated toward normalization of body tone to permit achievement of developmental levels.

    b. Appropriate sensory stimuli with a monitoring system based on the child's need and ability including olfactory, visual, auditory, tactile, and gustatory and kinisthetic.

  3. Enhancement of language development thru:
    a. Encouraging vocalization and its development into babbling, jargon, expressive speech.

    2. Recognition of symbols

    3. Encouraging family members to talk to the infant

    4. Help the child achieve normal milestones in social and emotional development, for example :

      1. Encouraging smiling response in blind child

      e. Enhancing ability of child to

distinguish between individuals

B. Education & Counseling of family members regarding
   1. Knowledge of normal growth and development
   2. Purposes of the Infant Program
   3. Community resources available
   4. Skills in coping with the problem
   5. Awareness of other families with similar problems

C. Staff Education would include:
   1. Training in basic child growth and development as necessary
   2. Making sure staff is well grounded and up to date in their present dicipline
   3. Cross-modality awareness
   4. Recognizing the need to learn from parents
   5. Training in interpersonal relations
   6. Sophistication in developmental techniques and relationships
   7. Up to date information regarding the nature of the disabilities with which they are dealing

D. Provision for remediation of basic defects, for example, removal of cateracts, hearing aid, etc.

7. Evaluation and Accountability

a) Instruments are available with which we can measure the child against his own baselines - for example:

1. Denver developmental
2. Reel in speech
3. Bailey

4. Mellani - Comperetti

b) Case study method
c) Subjective measurement of rather goals were achieved
d) Independent outside evaluator

8. Dissemination & Replication

a) Public education thru various media such as TV, newspapers, etc.
b) Professional education three professional journals, conferences, workshops, etc.
c) Assistance in replication thru:
    1. Provision of materials
    2. Provision of consultants
    3. Accepting visits from staff of other programs.
d) Responsibility for assistance in the training of undergraduate graduate students by means of university affiliations, etc.

0-18 MONTHS OF AGE

Our model is concerned with the family who has some concern and/or anxiety about the development of their infant. While it should be sponsored by UCP, it should serve anyone who seeks advice. We called this model a DEVELOPMENTAL INFORMATION CENTER. This Center should serve:

1) As a resource center for community education in child development.

2) As a center where any parent or child advocate can come to get advice and diagnosis and assistance. Anyone with concerns may opt for spontaneous walking into the center or for an appointment.

The Center is to be developed also as a resource for community education and should be equipped with films and other audiovisual materials, as well as a library and resource personnelle who can go into high schools, community centers, and others,as indicated, to "spread the gospel" on developmental patterns.

The koffeek lutch room should be warm and friendly, not at all like a hospital or clinic waiting room.

Philosophy behind the choice of the "receptionist-coordinator" is that this has to be a sensitive person skilled in interpersonal relations, who will not assume to diagnose, but give a direct report of the mothers stated concerns. She would have to explain to the mother, parents, or surrogate, the services of the Center and of the procedures to avail themselves of. She would also be the continuous contact person for each family.

Parents would have two options at the beginning of contact:

1) Appointment with the pediatrician for complete workup and/or further recommendations which may include referral to a well-baby clinic.

2) Visit from someone designated by the Home Service Director into the family home, this person to be chosen according to the descriptive need of the mother.

IN ALL CASES, BEFORE ANY SERVICES FOLLOWING THE INITIAL VISIT CAN BE PROVIDED THE PEDIATRICIAN HAS TO BE INVOLVED.

We consider it of utmost importance that parents see the pediatrician and the team in the koffeek room at the same day. Her evaluation has to be a continuous procedure, preferably in a very short period of time. The staffing of the team will be decided upon by the pediatrician, and so some of the mechanics here are still unclear in our minds, but the K.K. room evaluation will take the place for the moment of the more formal but also more threatening procedure. The purpose of the center, as stated before, is to deal with the diagnosis and realistic or unrealistic anxiety of parents, as other family members, followed by programming for each child.

Program: Emphasis placed is on options according to the immediate needs of each parent-infant group. And when we talk of families we are thinking in terms of extended families, (i.e. a grandmother may be the person most concerned).
Programs will be evolved to take place both in the home and at the Center. Social workers will have to be involved in all or most instances. Counseling for the extended family ongoing, and possible in an awy from home setting, is to be available. Babysitting and transportation has to be available.

Infant curriculum areas which were identified before time ran out were:

Nurturing procedures for both physical defects and for lack of feedback which may cause emotional distress. This nurturing includes feeding, bathing, holding, hugging, cooing, etc.

Sensory stimulation, starting with isolating of each sensory modality and leading to sensory cross modality stimulation, as well as all those special methods for hard of hearing or visual impaired or emotionality atypical babies.

Nutritional advice and guidance for parents.

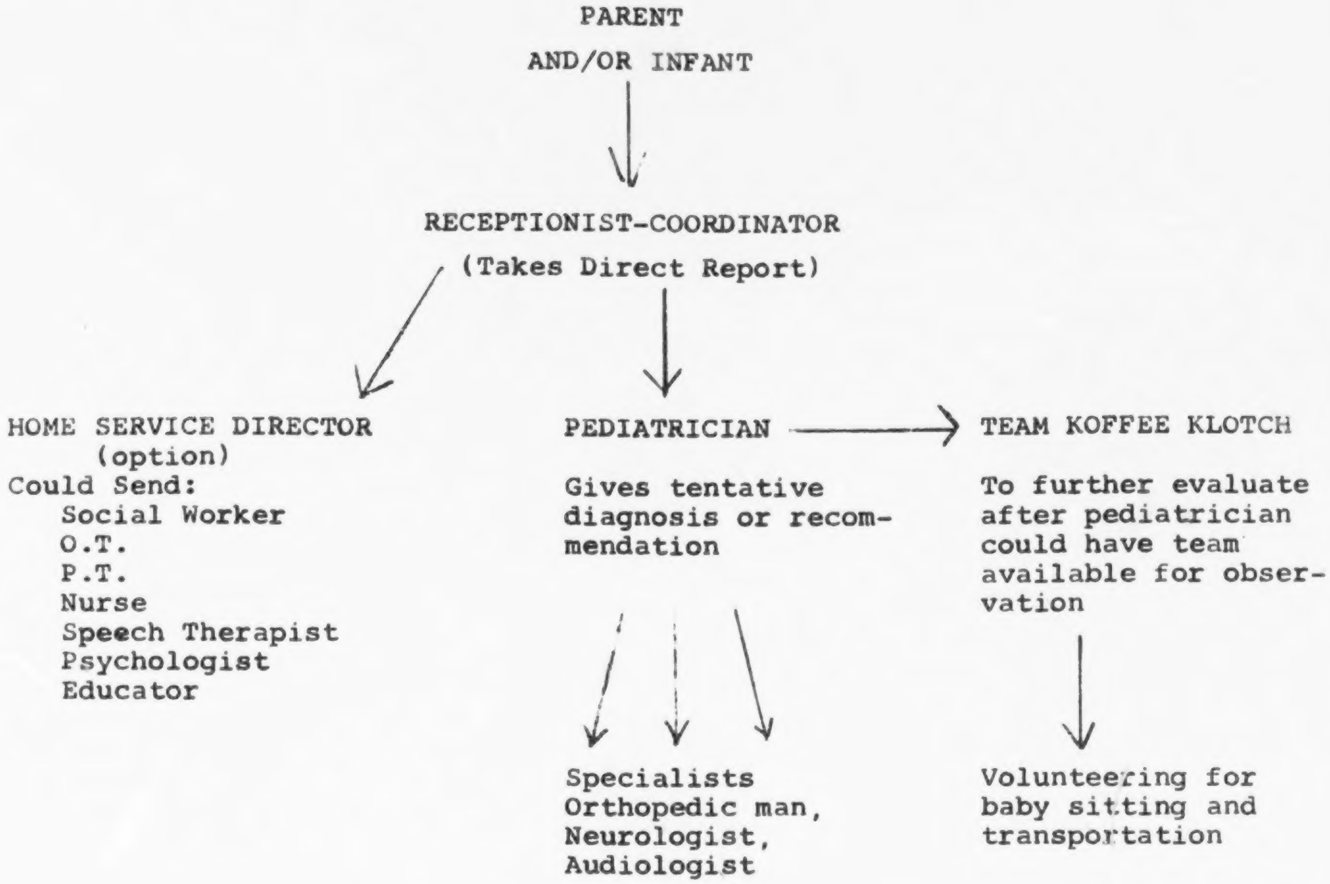
Verbal backup even where there is no feedback.

Physical stimulation and intellectual stimulation thru play. (No time for further details).

Definite assignments for mothers regarding developmental milestones.

Staff training to be ongoing and MUST include sensitivity session.

The group recommends that parents of handicapped children, who will be participating, must be an essential ingredient for future conferences, and thanks the mother of A.H.C. child in the group for providing realistic feedback for the group.


PARENT
AND/OR INFANT
RECEPTIONIST-COORDINATOR
(Takes Direct Report)
HOME SERVICE DIRECTOR
(option)
Could Send:
Social Worker
O.T.
P.T.
Nurse
Speech Therapist
Psychologist
Educator
PEDIATRICIAN
Gives tentative diagnosis or recommendation
TEAM KOFFEE KLOTCH
To further evaluate after pediatrician could have team available for observation
Specialists
Orthopedic man,
Neurologist,
Audiologist
Volunteering for baby sitting and transportation

Reassurance by staff that a program will begin.

Initial intake person or social worker is with parent throughout.

Model Program for 18-36 Months

The Components of our Model Program would be:

I. Who to Serve - All children with any type of involvement
ages 18 months - 36 months.
Two levels 18-24 months
24-36 months
with flexibility within total age range.

II. Size of Programs (Numbers) - As many as needs of community indicates and that quality program can be provided.
- group programs 6 for 18-24 months
8 for 24-36 months

III. How we get Children and Initial Intake - Child/family would come to us in many ways - referral from Professionals, Home Contacts, word of mouth, etc.
- Home Visits
- Screening
- Evaluation ideally done by entire team together and parents
- Developing a suggested future program for the total development of Child and his family.
- Channeling them into our Program services.

IV. Comprehensive and Overall Program - Services provided through 4 programs.

1. Home Program
(Child, Mother-------2. Individual Program
"Prime Programmer") 3. Group Program--(Size no more than 6 with 18-24 months 8 with 24-36 months)
4. Parent Program

V. Staff Necessary to carry out Program -
1. A Service Staff of all disciplines working as a team.
2. A Teaching Unit - in
1 trained teacher
1 aide
3. Use of Volunteers - trained supervised
given responsibilities

VI. Program Content - developed to aid the total child in areas of Emotional, Social, Physical Intellectual and Language/Communication Development.
- through providing Activities and Experiences in: gross Motor Activities
Fine Motor Activities
- Manipulative and Perceptual Activities
- Concept development - utilizing their environment and relating their environment to themselves
- providing: motivation sensory stimuli
- Self Image
- Success Activities etc.

- Curriculum: one based on the child' total life experience - past and future. One that would broaden their Horizons.

VII. Time Element within the program.

For Staff - All day
For Children - Longest time - half day
Individual scheduling
should be apart
Flexibility

VIII. Methods of Planning -

- Such a Model Program should understand and operate under objectives and purposes of our agency as a whole.
- Both programs as a whole and program for Individual Child should include setting Long time goals
  Short term goals
  Priorities

- Planning Methods to Accomplish and the doing
- Evaluation and re-evaluating check points from time to time
- Planning again etc.
- All through team approach.

IX. Parent Involvement - As important as child's being in our program.

1. Parent - staff inter-action a must realization of dual roles - of parents and staff - being both learners and teachers
2. Parent Involvement - could be in many ways:
   Conferences
   Home Visits
   School visits and involvement
   Counseling groups
   Coffee Hours
   Parent Meetings

Child Transportation - by parent is a most valuable involvement both for Parent/Child & program
(Sub-parent exchange - Volunteer Transportation)

X. Plans for Professional Growth and Development

1. Working schedule for Teaching Unit should be full-time with realistic salaries for quality program
2. Training of entire staff for total program before it starts: understanding total program
   "each others roles and talents
   Sharing
   Understanding Early Child Development 18-36 months

3. In service training
4. "Outside" training
5. Observation
6. Conferences, Meeting Conventions etc.
7. Good and open lines of communication

XI. Role of Agency, Our Program (18-36 mo.) - Community & Vice Versa

1. Seek out and plan for further program services for Child/family
2. Build a bridge between child's present program and future program
3. Aid in a smooth transition
4. Follow up and offer services if necessary

Parent & Teacher Conferences and Training for "us" with parents along. Needed now.

Notes on Use of Volunteers

Volunteer organization and set up is necessary.

Training - Orientation and on going is necessary to keep your volunteers interested and helpful.

Communication - daily (that is - 15 minutes before class and availability after class each day to relate as staff meeting type)

Responsible - for own substitute is helpful - understanding of this is necessary. Both Regulars and Substitutes are recruited.

Volunteer Chairman - is necessary and helpful to organization of volunteers.

Example of Volunteer Responsibilities in Nursery Pre-school program of 8 youngsters in a group - 1 teacher, 1 aide, 4 volunteers each period. Volunteer Involvement with all - 1 or 2 or more children in general activities. "You" are their playmates at this stage and also their conversationalists. Observe children - not to feel guilty when not "doing" a specific. Help with specific child/children and/or activity when asked.

Routine Responsibilities assigned per month to know routine things get done.

Snack Time - One Volunteer - prepare, serve, clean-up all other adults sit with children at tables to socialize.

Toilet & Wash - One Volunteer or two - be aware of needs, start 1 or 2 children toileting and washing at appropriate time. Others help.

Quiet Time - One Volunteer - get out mats and "Quiet toys" for suggestion - supervise - other adults will get involved with individual children.

Creative Materials - One Volunteer - check with teacher as to plans for day and help get things ready and clean up. All others help children as needed.

General Activities - ALL Involved.

3 - 5 YEAR OLDS

Curriculum - How possible with children with such a variety of problems from the minimal involvment to the multi handicapped.

All agreed - Deal three every day experiences and stimulations to help them deal with the realities they will face - Preferably on an every day basis.

Must Know Our Children

Since - curriculum implies long term goals

Felt - Curriculum should be flexible to allow for change and have short term goals.

Children should be allowed to have attainable goals and be able to experience the thrill of success.

What do we need: Team approach or cross modality
5 hour day 9 - 2
to give the child the maximum of what is offered.
Supervisor or director and office staff

Personnel Diagnostic Team (neurologist
(pediatrician
(psychologist
(orthopedist

P.T. - to facilitate learning in the classroom
O.T. - what the child can or cannot do
S.T. - advises teacher on skills to facilitate speech
Social Service Community resource people

Teacher
Teacher - aids
Home and volunteers
Service

Objectives - at this level

1. Make this child happy and a child you can live with
   Improve feeding techniques

2. Toilet trained - 1st real cognitive learning experience - teaching process which will help establish a primitive cycle in communication

   May then begin with a simple language skill and develop it

3. Establish communication -

4. Work on attitudes - toward others
   Sharing and himself
   Waiting his turn

5. Parent Education
    Group meeting - a nite can include fathers
    with social worker and/or home service
    Individual counseling sessions with staff members.

Never did get a building

other than one level with ramps
and enough bathrooms

Felt however that we found the groups interesting - very helpful and insight into the problems others face. - We are not alone in problems.

What we need!

A Child -

Composite Child - Athetoid
Boy - C.A. 4 years
Severely retarded M.A. - 9 months
Non verbal - Babbles with vowel sound at 4 month level
Not toilet trained
Must be fed
Creeps independently, crawls with assistance
Hearing - OK
Eyes focus - Adapts the circle to Benet form board
Smiles - Responds to his name
No - tactile or proprioceptive responses

Family - Parents are American of average intelligence
Brother 16
Sister 9
Discussed other factors in the home which would affect the child (religion, social standing, ethnic background, acceptance or non-acceptance of the child by the family).

Before the child entered

Reports needed - (Early diagnostic
(Early developmental
(Early socialization
(Family social history
(Home Service Reports